

# **Residents' Experiences of Moving from Home into a Care Home: A Grounded Theory Study**

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*I confirm that the word count of this thesis is less than 40,000 words*

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## Dedication

**To Ellen, James and Sean who will always be ‘forever young’.**

*May God bless and keep you always  
May your wishes all come true  
May you always do for others  
And let others do for you  
May you build a ladder to the stars  
And climb on every rung  
May you stay forever young  
Forever young, forever young  
May you stay forever young.*

*May you grow up to be righteous  
May you grow up to be true  
May you always know the truth  
And see the lights surrounding you  
May you always be courageous  
Stand upright and be strong  
May you stay forever young  
Forever young, forever young  
May you stay forever young.*

*May your hands always be busy  
May your feet always be swift  
May you have a strong foundation  
When the winds of changes shift  
May your heart always be joyful  
And may your song always be sung  
May you stay forever young  
Forever young, forever young  
May you stay forever young.*

Forever Young (Bob Dylan, 1973)

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## Abstract

**Background:** Globally, along with population ageing, there is an increasing trend for older people with complex care needs to reside in care homes. It is recognised that moving into a care home can be a complex and emotional experience for the individual and their families. Despite this, there is a paucity of research that takes into consideration individuals' experiences of the first year of life in a care home.

**The study:** A grounded theory methodology was employed to undertake semi-interviews with participants (n=23) who were moving from home to a care home over the course of a year. The interviews were carried out at four key time points: 1) pre-move (7 days) or post-move (within 3 days); 2) at four and six weeks; 3) at 4-5 months; and 4) at 9-12 months post move.

**Findings:** Three core categories were identified at key timepoints of the move: 'You're at their Mercy' when participants perceived a sense of disempowerment throughout the admission process; 'Waiting and Wanting' when in the early weeks post move participants were disillusioned by a loss of independence, autonomy and continuity of former roles; and 'The Primacy of 'Home' when at the latter end of the year post move, participants placed substantial meaning on preserving their identity and finding connections both within the care home and with 'family and home'. The story line for the first year of the transition to a care home was captured in an overarching category '*The centrality of connection in supporting older people on their journey from life at home to life in care home*'. The theory that emerged suggests that care home residents who are connected, as evidenced by their participation in decision making about the move and the extent to which they can maintain existing connections to home and family while at the same time, creating new connections within the care

home environment, have a more successful transition to life in a care home than individuals who do not have this connectedness.

**Conclusion:** This study increases understanding about how older people make a positive adaptation to living in a care home. It was recognised that facilitating individual preferences and expectations from the outset can empower people to progress towards acceptance of the move. Health care professionals have a key role to play in collaborating with older people around decision-making, planning and moving to a care home.

## Abbreviations

<b>AIGNA</b>	All Ireland Gerontological Nurses Association
<b>DHSSPS</b>	Department of Health Social Services and Public Safety
<b>DOH</b>	Department of Health
<b>LTC</b>	Long Term Care
<b>NHS</b>	National Health Service
<b>NI</b>	Northern Ireland
<b>NIAO</b>	Northern Ireland Audit Office
<b>NICE</b>	National Institute for Health and Care Excellence
<b>NISRA</b>	Northern Ireland Statistics Research Agency
<b>ONS</b>	Office for National Statistics
<b>RQIA</b>	The Regulation and Quality Improvement Authority
<b>SCIE</b>	Social Care Institute for Excellence
<b>UK</b>	United Kingdom
<b>UN</b>	United Nations
<b>USA</b>	United States of America
<b>WHO</b>	World Health Organisation
<b>WHST</b>	Western Health and Social Care Trust



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# **CHAPTER ONE:**

## **INTRODUCTION**

### **1.1 Introduction**

The aim of this PhD was to explore the experiences of older people making the transition from home to a care home over a one-year period. Chapter One introduces the background, context, and rationale for the proposed study. The researcher's perspective is also presented which provides insight into the researcher's background, and how this led to the commencement of a PhD. The chapter ends with a summary of study aims and objectives and an overview of the thesis structure.

### **1.2 Background and Study Context**

Population ageing is a global phenomenon with almost every country in the world experiencing a significant rise in the proportion of their older citizens. In 2019, there were 703 million people aged 65 years or over worldwide. This figure is projected to double to 1.5 billion in 2050 (United Nations (UN) 2019a). Population ageing is primed to become one of the most noteworthy social transformations of the 21<sup>st</sup> century. These changes will have implications for almost all sectors of society including housing, transportation, and social protection, in addition to family structures and intergenerational connectedness (UN 2019).

The Office for National Statistics (ONS 2018) determine that the United Kingdom's (UK) population is ageing with almost 12 million (11,989,322) people aged 65 years and over. In Northern Ireland (NI) the ageing population has grown with the number of those aged 65 years and over increasing by 1.8 per cent in 2017 to reach 303,000

people (16.2 per cent of the population), (Northern Ireland Statistics Research Agency (NISRA 2018). As the ageing population increases, so too do the levels of complex health care needs of people living with co-morbidity, dependency, and dementia (Kingston *et al.* 2018); requiring both informal and formal social care services (Kelly and Kenny, 2018). Within the UK the percentage of people with co-morbidities among those aged between 65-74 years is 46%. This percentage increases to 69% amongst those aged 85 years and over (Kingston *et al.* 2018).

Globally, around 50 million people are living with dementia. This number is predicted to reach 82 million in 2030 and 152 million by 2050 (WHO, 2020). In 2019, more than 920,000 people in the UK were reported to be living with dementia. Moreover, the number of older people with dementia in the UK is projected to increase to around 1.6 million in 2040, (Wittenberg *et al.* 2019). In relation to care homes, the total prevalence of dementia is estimated at 69.0% (62.7% for males and 71.2% for females) (Dementia UK, 2014). It is projected that the probability of living in a care home increases with the severity of dementia. Therefore, into the future, a higher proportion of people with dementia are expected to live in care homes rather than receive care in the community (Wittenberg *et al.* 2019). Generally, individuals residing in care homes, including those with dementia, have been absent from research (Davies *et al.* 2014) due to difficulties in recruitment (Goodman *et al.* 2010; Wilson *et al.* 2010). Some reasons put forward have been the cognitive and physical frailty of residents, heavy staff workloads, staff turnover, different managerial approaches and varying opinions concerning research, all of which make care home research unpredictable (Luff *et al.* 2015). Furthermore, care home research may pose ethical

challenges because many of the residents are cognitively impaired and may have issues with capacity and providing consent (DiazOrdaz *et al.* 2014).

In addition to dementia, frailty is a significant problem associated with older age. A longitudinal study undertaken in England found that the number of people living with frailty rises with age, 6.5% in those aged 60-69; and 65% in those aged 90+ (Gale *et al.* 2015). Moreover, older people living with frailty are at increased risk of disability, hospitalisation, care home admission and death (Wirral 2018).

Globally, in tandem with population ageing, there is an increasing trend for older people with complex care needs to reside in care homes, which poses challenges for health and social care systems, (WHO 2018). Within the UK in 2017, there were approximately 17,678 care homes caring for 426,000 older people (Age UK 2017). In NI on 1 October 2018, there were 16,007 listed beds in all registered nursing and residential care homes. This represents a 4% increase in the total number of beds in the sector over a ten year period. These statistics highlight the implications of an ageing population and the necessity for a comprehensive understanding of older people's care needs including the requirement for long term care provision.

Moving into a care home is a significant life event for older people and the relocation normally occurs at a point in life when an individual is at an advanced age with increasing likelihood of multi-morbidities and dependency (Marengoni *et al.* 2011; Barnett *et al.* 2012; Ryan and McKenna 2015). Conversely, if individuals perceived that they had no choice about moving they experienced higher levels of sadness, anger, loneliness, and depression compared to those individuals who were involved

in the decision-making process (Brownie *et al.* 2014; Bowers *et al.* 2015). Adapting to life in a care home can be a complex and emotional experience for older people (Brandburg *et al.* 2013; Ryan and McKenna 2015). In terms of adjustment to a new care home environment, Chenitz (1983) developed a mid-range theory on care home entry. This involved a number of key concepts that influence the adjustment process which were: (1) centrality, as in the perceived importance of the move in maintaining a sense of independence, autonomy and control; (2) desirability, the extent to which the older person perceives the move as being desirable and undertaken out of choice rather than necessity; (3) legitimization as in finding a plausible reason for the admission which came from a variety of sources e.g. family, physicians, social workers, nurses etc and (4) time and duration as in length of stay being on a temporary or permanent basis. When honest answers about the duration of stay were not given, older people suspected their admission was irreversible. According to Chenitz (1983), when irreversibility was combined with undesirability, lack of voluntary participation and no legitimization, the older person resisted admission.

In contrast, Nolan *et al.*'s (1996) research has suggested that moving to a care home is more likely to be regarded as a positive choice if four features are present. These are (i) anticipation (the extent to which prior thought and discussion have been given to the placement); (ii) participation (the extent to which the older person and carers participate in decision-making processes); (iii) information (quality of information and advice); and (iv) exploration (a consideration of alternatives and emotional responses). This suggests that the transition to life in a care home starts prior to the move. Likewise, the extent to which residents can exercise control over the decision

to move is acknowledged to have a major influence on their overall experience of this significant life event (Johnson *et al.* 2010; Ryan and McKenna 2015).

Transitions, including the move to a care home, are characterised by different dynamic stages, or turning points and can be established through processes and outcomes (Eika *et al.* 2014). Thus, while transition is considered a natural process brought about by the changes in our lives, the transition to a care home represents a uniquely significant relocation for older people. Bridges (2004) defined transition as a psychological reorientation with three distinct phases: (a) endings that involve letting go and experiencing loss in some form, (b) a neutral zone that is an in-between phase, usually associated with uncertainty and (c) the new beginning that may involve a new focus or new identity. Furthermore, the duration and extent of the ‘transition’ process has been defined as continuing until the adaptation to changes in one’s life is complete. Thus, the transition process can subsequently produce fundamental changes to an individual’s role or identity (Porter and Ganong 2005; Wiersma and Dupuis 2010). It is contended that care home transitions are oversimplified by assertions that individuals follow set phases in adjustment, or by describing positive adjustment by determining single aspects of functioning (Marshall and McKenzie 2008). Furthermore, older people’s perspectives of moving to a care home have been inadequately investigated (Backhouse *et al.* 2016). In view of the paucity of research that takes into consideration the perspective of the individual making the move, this study aimed to elucidate the ongoing processes of their care home transition.



### **1.3 Researchers Perspective**

It is difficult to understand how a researcher's personal and professional knowledge, life experiences and philosophical position, could not influence the research process in its entirety. For this very reason, the researcher's background and professional experience plays a significant part in the motivation for investigating the phenomenon of study. Cleland (2017) postulates that differences in ontological and epistemological assumptions can guide study design, emerging data and analysis, conclusions drawn, and the recommendations made from the findings of the study.

I grew up in a country area in a time when everyone knew their neighbours. From a young age, I remember my mother encouraging me and my brothers to visit a retired pharmacist and his wife and a farmer who both lived approximately half a mile from our home every Friday evening to have a cup of tea and to 'ceilidh' with them for an hour or so. These visits involved bringing my mother's scone bread for the tea, then we spent an hour or two playing cards, hearing their life stories, listening to the fiddle and often getting turf from the shed for the fire so that we could tell my mother we had 'helped out' when we were there. I look back on those days and consider how much we valued and respected older people, how much we enjoyed the 'craic' and considered this Friday night ritual to be part of normal country life. I now live approximately three miles from my family home. As neighbours we still know most people living close by, but I don't think that we have a natural affinity to spend time with older people. We have a formalised voluntary scheme for bringing dinners to older people who live alone, but I feel it relates more to social conscience.

My chosen career as a nurse was undoubtedly influenced by my mother, an adult nurse and midwife and my aunt who was a learning disability nurse. I had considered teaching as a career but was easily persuaded to apply for nursing and I left home at seventeen to undertake my adult nurse education in England. It is interesting now to realise that after spending over 20 years in nursing, I went on to be a nurse lecturer, a role I have had for almost 17 years. In essence I have perhaps come full circle, having got to 'be a teacher' in the end.

My adult nurse training was a life changing event for me for two reasons. Firstly, my father was diagnosed with cancer and died aged 51 years within three weeks of discharge from hospital. This was during my first year of nursing when I was home on Christmas leave. I felt so sad and proud to be able to use my newly acquired nursing skills to assist him in the last few weeks of his life. His death had a profound effect on me, and thereafter I have always been mindful of the earth-shattering effect a cancer diagnosis has on the lives of the individual and their families. The second reason my adult nurse training had such an impact on me was because of the part I had to play in supporting particular patients and their families who experienced horrendous accidents and incidents including children and adults being diagnosed with life limiting illness, accidental deaths, victims of assault, and people who wanted to end their own lives. I learned a lot about myself professionally and personally in terms of how I respond to things that I am faced with. I always enjoyed being part of the team and undertaking a clinical role responding to emergencies and the need for quick actions and responses. More significantly I never considered the task complete until I had provided psychological support to those individuals undergoing the trauma. I gained a reputation with my colleagues as someone who was good at 'having those

difficult conversations' and was often put forward to look after the person or the family during these difficult times.

I think these experiences were the catalyst for me to undertake my mental health nurse training and after completion, I held positions as a ward manager and community mental health nurse. I found that these nursing experiences allowed me to become a truly autonomous practitioner and I felt as if I had developed my own moral compass and core values for the nurse manager I wanted to be. On return to Ireland some 10 years later, my mother was diagnosed with Syringomyelia and died two years later at the age of 63. I was fortunate to look after her during the last two years of her life and I feel blessed that we made those last two years as good as they could have been with her condition.

After my mother's death, I managed a residential home for a number of years and was responsible for deriving new practice initiatives in relation to caring for our residents and service provision. This role permitted me to work in liaison with various external agencies who directed service provision within Northern Ireland. I believe that the expertise and experience I gained in clinical practice has enabled me to gain insight into the role of a care home manager. My clinical interest in gerontological nursing and the care of older people has continued in my academic role through my teaching in the undergraduate and postgraduate curriculum. In addition, I have been an active committee member of the All Ireland Gerontological Nurses Association (AIGNA) for several years. The organisation has a growing influence on policy, strategy, research, education, and practice within Ireland. Members are nurses who work with older people across a range of different care settings. They are supported to promote

healthy ageing and well-being of older people through the provision of an annual masterclass and conference, having access to evidence-based practice materials and research. The ultimate aim is to strive for excellence in gerontological nursing. Furthermore, the 'gerontological nurse' voice is heard at these events by presenting practice development initiatives and sharing good practice.

In 2012, I was successful in gaining an Institute of Nursing Fellowship from Ulster University to undertake a research study led by Professor Assumpta Ryan with psychology colleagues. The aim of the research study was to determine the prevalence of mental health disorders among older people in care homes within the Western Health and Social Care Trust (WHSCT). This information was directly compared with data already collected in a societal study of mental health in Northern Ireland (NI). The NI Study of Health and Stress (NISHS) (Bunting *et al.* 2011) was one of the largest population studies of mental health undertaken in NI. For my fellowship, I completed a cross-sectional study to determine the levels, types, and correlates of mental health problems amongst 75 older people living in nursing and residential homes. I then compared the results with data collected from a matched sample of community dwelling older adults from the NISHS study. Results showed a low prevalence of mental health disorders among care home residents in comparison to community dwelling older people. Of reported significance were individuals' perceptions of overall quality of life, including related values such as well-being, happiness, and life satisfaction. The results challenged the view that the mental health needs of care home residents were neglected. They also raised questions about mental health and quality of life among community dwelling older people (O'Neill *et al.* 2020). These results prompted me to think about the factors that influence an

individual's perception of living a positive and fulfilling life in a care home and this ultimately triggered my interest in pursuing this issue further in a doctoral level study.

#### **1.4 Rationale of Study**

In the United Kingdom (UK), social care provision is a devolved responsibility which has brought about some variance in social care policy across the UK, along with policies that promote person-centred care (Chapman 2019). In Northern Ireland (NI), there have been three major reviews of the health and social care system since 2010. Transforming Your Care (Department of Health Social Services and Public Safety (DHSSPS) 2011) proposed the implementation of an integrated health and social care provision model. This strategy recommended a major shift to care being delivered within people's homes and a greater access to care services in the local community. The review also proposed a shift away from residential care with those needing 24 hour care to be cared for in nursing homes. Despite the strategic vision for Transforming Your Care (DHSSPS 2011) the impact has been more limited and plans for the implementation have lacked the necessary strategic and statutory backing to be enacted (Northern Ireland Audit Office 2017). The Donaldson Report (2015), examined the application of health and social care governance arrangements for ensuring the quality of care provision in NI, and more recently, the Bengoa Report (DHSSPS 2016) has emphasised the need to move services into the community to relieve the pressures on acute hospitals. In essence, these reviews have largely focused upon health service reform rather than adult social care.

Strategic policy drivers for older people's health and social care in NI have included 'People First: Community Care in NI' (DHSSPS 1990) which identified that community care services should address individual need with the provision of care packages. 'People First' continues to underpin the provision of community care in NI. The Caring for Carers Strategy (DHSSPS 2006) was specifically designed to recognise, value and to support the caring role. In 2010, Living well: Dying well- A palliative and end of life care strategy for adults in NI (DHSSPS 2010) identified the need for physical, spiritual, psychological, financial, and social support. The Regional Strategy for Improving Dementia Services in NI (DHSSPS 2011) made recommendations aimed at improving the services and support arrangements available for people with dementia, their families, and carers. In 2012, The Northern Ireland Human Rights Commission published an investigation 'In Defence of Dignity - The Human Rights of Older People in Nursing Homes'. The Commission called for legislative and policy measures to explicitly link human rights standards with nursing home care, to ensure that care delivery improved the lives of residents. Thereafter, The Service Framework for Older People (DHSSPS 2013) set standards in relation to person-centred care; health and social wellbeing improvement; safeguarding; carers; conditions more common in older people; medicines management and transitions of care.

Adjustment to care home life is a process that occurs over time. Part of understanding this process requires recognition of variances in the responses of older adults whose permanent move to a care home was either planned or unplanned. Research into the experiences of older people moving into a care home facility have tended to focus on the physical changes that take place rather than the psychological and/or social

changes that these transitions may also involve. Even where other dimensions of change are studied, these are usually from a service rather than an older person's perspective. Some researchers have focused on describing the experiences of older adults and carers as they adjust to care home life and factors that influence their adjustment (Kao *et al.* 2004; Davies and Nolan 2006; Voutilainen *et al.* 2006; Horner and Grenade 2007). Moreover, there is a lack of research that takes into consideration the total relocation process, incorporating residents' experiences with the move, a stage in the process found to be important when families relate their experiences with relocation (Davies and Nolan, 2006; Sussman and Dupuis, 2014). It is evident that complex and multidimensional factors can influence the adaption process for older people when relocating to a care home (Bradshaw *et al.* 2012; Brownie *et al.* 2014; Krizaj *et al.* 2018). Older people themselves are often not involved in research processes even when studies are care-home focused (Backhouse *et al.* 2016). Furthermore, there is a paucity of research that takes into consideration the entire relocation experience from pre residence to up to one year after the move, and the extent to which individuals can be facilitated to feel 'at home' in a care home environment. This study aims to address the dearth of research in this area. It is predicted that the knowledge gained will inform care delivery in determining the nature of ongoing support needed by individuals in their transition to life in a care home.

## **1.5 Research Aim**

Consistent with a grounded theory methodology, the broad aim of this research study was to explore older people's experiences of moving from home to a care home over four time points during the first year of the move.

### **Broad Research Objectives:**

- To explore participants' perceptions of the circumstances surrounding the decision to move to a care home.
- To explore the factors influencing participants' experiences of the first year of their transition to life in a care home.
- To develop a substantive theory contributing to our understanding of the factors supporting a better transition from living at home to living in a care home.

## **1.6 Care Home**

In the context of this thesis, the term 'care home' is used to encompass both residential and nursing homes. A residential care home provides accommodation with both board and personal care for persons by reason of old age and infirmity; disablement; past or present dependence on alcohol or drugs; or past or present mental disorder. Residential homes do not provide nursing care. A nursing home is any premises used, or intended to be used for the reception of, and the provision of nursing for persons suffering from any illness or infirmity. Some homes are registered to care for people in need of both residential or nursing care (The Regulation and Quality Improvement Authority, 2020). The rationale for including residential homes in this study recognises the complexity for residential care home staff in supporting individuals



with high levels of healthcare needs. It has been identified that variations in staff skill mix, inequity in health care support and challenges of building good relationships with General Practitioners and District Nurses can prevent residential care home staff from managing the healthcare needs of their residents (Dudman et al. 2018).

## **1.7 Thesis Structure**

Unlike the traditional presentation of a doctoral thesis which normally comprises 80-100,000 words, this thesis is presented as a *PhD thesis with papers* format. Ulster University has provision for this format ([www.ulster.ac.uk/doctoralcollege](http://www.ulster.ac.uk/doctoralcollege)) as it has the potential for prompt dissemination of research findings, for training and supporting PhD researchers to acquire journal article writing skills and to be more efficient in presenting research material. This format is characterised by a shorter word length (circa 40,000 words) and the inclusion of a minimum of three papers submitted for publication. Consistent with Ulster University guidelines, neither the papers nor the other chapters on their own, constitute the thesis. Instead, the thesis represents a coherent body of work which should be complete and comprehensive. In using the *PhD thesis with papers* format, only parts of this thesis written as a paper are briefly summarised in the text of the thesis so as to avoid unnecessary repetition. As with other qualitative studies, and to avoid any awkwardness or confusion related to using the term 'researcher' or 'author', the first person will be used. The structure and content of the chapters in this thesis are summarised in Table 1.1 below.

**Table 1.1: Structure of the Thesis**

Chapter	Title	Contents
Chapter One	Introduction	Chapter one introduces the thesis and presents an introduction to population ageing, strategic policy drivers for older people's health and social care, and rationale for the study. It also provides details of the researcher's perspective and the broad research aims and objectives. Finally, the structure of the thesis is presented.
Chapter Two	Literature Review	In keeping with the use of a grounded theory methodology, a comprehensive literature review was not undertaken until data collection and data analysis were concluded. This chapter provides an integrative literature review exploring the transition of older people to a care home environment which was undertaken at the end of the data collection.
Chapter Three	Methodology	This chapter explains the philosophical underpinnings of grounded theory and the methodology utilised. The rationale and techniques employed for data collection and analysis are discussed and the chapter concludes with a discussion on the strategies employed to ensure credibility of the study's findings.
Chapter Four	Findings	This chapter presents a description of the findings of interview stage one (Pre-move/up to 7 days post move), Interview stage two (4-6 weeks) and Interviews stages three (5-6 months) and four (9-12 months). There are three published papers presented within the findings chapter relating to these key time points. The findings are outlined in accordance with the paradigm model described by Strauss and Corbin (1990; 1998). The chapter concludes with the presentation of the theory ' <i>The centrality of connection in supporting older people on their journey from life at home to life in care home</i> ' generated from the study.
Paper One	Findings Interview Stage One	' <i>You're at their Mercy</i> ': Older peoples' experiences of moving from home to a care home: A grounded theory study. Published in the International Journal of Older People Nursing, e12305. <a href="https://doi.org/10.1111/opn.12305">https://doi.org/10.1111/opn.12305</a>

Paper Two	Findings Interview Stage Two	‘Waiting and Wanting’: Older peoples’ initial experiences of adapting to life in a care home: A grounded theory study. Published in Ageing and Society, 1-25. <a href="https://doi:10.1017/S0144686X20000872">https://doi:10.1017/S0144686X20000872</a>
Paper Three	Findings Interviews Stages Three and Four	‘The Primacy of ‘Home’: An exploration of how older adults’ transition to life in a care home towards the end of the first year. Paper Accepted in the Health and Social Care in the Community Journal (Appendix 1).
Chapter Five	Discussion	This chapter discusses the key findings of narrated time points in relation to existing literature and the originality therein. The findings are also compared to other theoretical perspectives and related to the substantive theory generated in Chapter Four.
Chapter Six	Conclusions and Recommendations	This final chapter highlights the implications of the research study for policy and practice and makes recommendations for further research. The limitations of the study are discussed, and final conclusions made.

## 1.8 Chapter Summary

This chapter has provided the background and context to the thesis by outlining key demographics relating to population ageing and the necessity for long term care for older people within health and social care provision. The complexities of care home admission have also been highlighted. The researcher’s personal perspective has been identified. Thereafter the study’s broad aim and objectives were outlined followed by a planned structure for the thesis. In the next chapter an integrative literature review exploring the transition of older people to a care home environment will be presented.

## **CHAPTER TWO: LITERATURE REVIEW**

### **2.1 Introduction**

The previous chapter provided the background and context to the thesis by outlining the necessity for health and social care provision for an older population and the complexities of care home admission. The aim of this chapter is to present an integrative literature review exploring the transition of older people to a care home environment. The chapter begins with a discussion on the purpose of a literature review in grounded theory and then presents the integrative literature review. Due to word restriction, an integrative review synopsis is provided at the end rather than an in-depth discussion. However, the significance of the literature review findings will be discussed in the context of the study findings in chapter five. The chapter ends with a summary of the overall literature findings.

### **2.2 The purpose of the literature review in grounded theory**

In qualitative research, the literature is traditionally appraised prior to the commencement of the study to explore the area of interest and to determine knowledge about the subject area (Polit and Beck 2012). Similar definitions of a literature review can be seen across many disciplines, and usually the literature review is seen as a: “critical component of the research process that provides an in-depth analysis of recently published research findings in specifically identified areas of interest” (Houser 2018, p. 109). The rationale and requirement to undertake a literature review within the research process warrants significant consideration (Creswell 2014; Polit and Beck 2014). Academics differ on how extensive and at what stage of the research process, the literature review should take place, and this is

particularly relevant in terms of the design and method chosen by the researcher (Dey 1999; Polit and Beck 2012; Saks and Allsop 2013).

Moreover, in the context of grounded theory research, the deliberation about how and when the literature should be consulted has been the subject of considerable discussion and debate. Glaser and Strauss (1967) and Glaser (1978) highlighted the importance of starting research with as little-known theory as possible. The purpose of this is to ensure that theoretical themes are generated from the data, rather than from preceding research and theory. In this context, a comprehensive literature review is contrary to the principles of grounded theory. Glaser (1992) firmly advised that the literature review should be delayed until after empirical data collection. In contrast, Strauss (1987) advocated extensive reading in related topics while delaying reading in the substantive subject area until data collection was complete. A decade later, Strauss and Corbin (1998, p. 36) emphasised the importance of using accumulated knowledge during grounded theory data analysis, stating “there is always something new to discover”. Whilst Glaser (1998), acknowledged the practical difficulties of delaying the literature review, he remained staunch in his position that the literature review should be delayed. Glaser’s stance is not without support. Nathaniel (2006) endorsed this argument, whilst Holton (2007, p. 269) was also decisively traditionalist in her view, arguing that ‘grounded theory required the researcher to come into the research arena with no predetermined problem statement, interview protocols, or comprehensive review of literature’. Charmaz (2006), on the other hand argued that the literature review provides an opportunity to identify and evaluate the pertinent literature as well as help the researchers position themselves amid current discourse. Consistent with Glaser (1998), Strauss and Corbin (1998) acknowledged that it is

impossible to appreciate what the significant problems will be prior to the examination or what theoretical concepts may emerge. They also acknowledged the risk of being so immersed in the literature that the researcher could become constrained by it, but conceded that if the literature is used appropriately, it also becomes a source of meaningful and relevant data.

My theoretical sensitivity had been influenced by professional experience and prior knowledge of undertaking a research study that investigated 'Mental Health, Quality of Life and Medication Use Among Care Home Residents and Community Dwelling Older People' (O'Neill *et al.* 2020). Therefore, trying to disregard these influences was futile. Furthermore, in developing a research proposal for funding and ethical approval, it would have been very challenging to persuade a research committee, that background knowledge of the proposed research study was not necessary. With this awareness, the important challenge was to make the best use of my theoretical sensitivity by striving to keep an open mind and being reflexive during data collection and analysis, and by following the principles of constant comparative analysis. This ensured that explanations that emerged from the data were sought, rather than deducing what was transpiring from predetermined ideas. This methodological approach is endorsed by McGhee *et al.* (2007) and Walls *et al.* (2010) who suggest that previous knowledge and clinical experience should not compromise a grounded theory study provided the researcher uses reflexivity and articulates the potential influence of their background on the research process. Consequently, and consistent with grounded theory methodology, a comprehensive literature review was not undertaken until data collection and data analysis were concluded and the categories and core category emerged. Thereafter, as suggested by Corbin and Strauss (2008),

data was enriched by examining further literature in a more focussed and comprehensive manner.

### **2.2.1 Background**

The population of the world is ageing (WHO 2018), and internationally, there is an increasing trend for older people with complex care needs to live in care homes. It is recognised that the transition from living at home to living in a care home is a uniquely significant experience for older people that can be a stressful, challenging and an emotional process for individuals and families, as it involves a major adjustment in their daily lives (Ellis 2010; Brandburg *et al.* 2013; Sury *et al.* 2013; Ryan and McKenna 2015). Relocation to a care home normally occurs at a point in life when an individual is at an advanced age with increasing likelihood of multi-morbidities and dependency (Marengoni *et al.* 2011; Barnett *et al.* 2012; Ryan and McKenna 2015).

### **2.2.2 Aim**

The aim of this literature review is to identify and critique pertinent literature about the experiences and perceptions of older people during the transition to a care home.

## **2.3 Methods**

An integrative review includes both experimental and non-experimental research, thus facilitating the mapping of studies from different branches of science to integrate and synthesise knowledge about a particular phenomenon to reach new insights and conclusions (Whittemore and Knafl 2005; Gough *et al.* 2012). This wider mapping of studies was supplemented by searching sources without time limits, since limiting literature searching can introduce bias (Cooper *et al.* 2018). The quality of the research

papers selected for review were assessed using the preferred reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) reporting system (Moher *et al.* 2009), and the Critical Appraisal Skills Programme (CASP) (<http://casp-uk.net/criticalappraisal>).

### **2.3.1 Study selection and exclusion criteria**

The literature review was guided by Whittemore and Knafl's (2005), integrative review framework. This framework provides a systematic method of examining research from varied empirical and theoretical sources which enhances the rigour of the integrative review process. The integrative review approach starts with problem identification and its related concepts, with the intention of obtaining data from the primary sources. It then defines distinct literature search strategies, incorporating search terms, inclusion, and exclusion criteria in order to evaluate the importance of the primary sources. Thereafter, data evaluation takes place by examining the quality of primary papers against gold standard measures e.g. Critical Appraisal Skills Programme Tools (CASP 2018). After the most eligible primary sources are identified, studies are organized into groups and subgroups for the purpose of data extraction and reduction. The data are organised to create patterns, relationships, and variation among the concepts. This data reduction stage reinforces qualitative research iterative methods of analysis. Lastly, conclusions are derived and verified so that the complexities of the relevant literature are summarised in a logical sequence of evidence.

This literature review provides a rigorous representation of the literature focussing primarily on peer-reviewed journals that were conceptual and empirical. The



following paragraphs describe the search terms, databases used, additional search strategies and the inclusion and exclusion criteria for determining the relevant sources. This literature review included articles that (a) considered older people's experiences before and during the transition to a care home environment; and (b) considered the older person's view of what supported and hindered the transition process. Studies were excluded if the research focused specifically on the sole view/opinions of relatives or care staff.

### **2.3.2 Data sources**

The search strategy was formulated with the support of a library manager who assisted with the identification of key databases. The search was limited to peer reviewed journal articles written in English. Key search terms and synonyms using Boolean search options (Cronin 2008) were: (elderly or aged or "old\* people" or "old person\*" or geriatric\* or older or senior) AND (transition or move or transfer or admission or relocate\*) AND (experience\* or view\* or attitude\* or adjustment or adapt\* or opinion\* or feeling\*) AND ("nursing home\*" or "residential home\*" or "long term care" or "care home\*" or "residential care facility\*"). Searches were conducted using four electronic databases: Cinahl Complete, ProQuest Health and Medical Collection, PyscINFO and Scopus. A supplementary search strategy was employed by searching the reference lists of all included studies. Grey literature searches were conducted using British Nursing Index, and Google Scholar.

The database searches identified a total number of 2,169 articles. After removal of duplicates, 1,514 papers remained. Paper selection and screening included reviewing the titles and abstracts (when available) and applying the inclusion and exclusion

criteria. After this process, 1,440 papers were excluded. A total of 74 full-text sources were screened and assessed for eligibility. Papers excluded focused on relatives' experience of care home admission, hospital admission and discharge to and from care homes, housing needs, health and mobility, palliative care, risk assessment, advanced care planning and student nurses' care home experiences. Secondary sources of literature were also excluded. These exclusions resulted in 29 papers. The reference lists of all included papers were scrutinised, and one additional paper was identified. This resulted in 30 papers. One paper was subsequently excluded in the evaluation process, resulting in a final total of 29 papers included in the literature review.

### **2.3.3 Data evaluation**

The full text of all the articles (n=30) were evaluated independently by the research team. The quality of the qualitative studies (n=22), and the systematic reviews (n=8) were assessed using the Critical Appraisal Skills Programme (CASP) (<https://casp-uk.net/casp-tools-checklists/>) checklist for qualitative studies (n=22) (Appendix 2) and the CASP checklist for systematic reviews (n=8) (Appendix 3). The CASP checklists both have 10 questions that relate to rigour, reliability, and credibility of the studies. Questions are answered with either yes, cannot tell, or no. Each question is given a score based on a response of yes, no, or can't tell. Every yes response merits a score of 1. Articles that attained a summation score <6 were not included in the analysis. One study scored a CASP of 5 and was therefore excluded, resulting in a total of n=29 studies that met inclusion criteria.

### **2.3.4 Data Analysis**

Data analysis was facilitated by becoming familiar with the data through several appraisals and critical reviews of each published paper. Consistent with Whitemore and Knafl's (2005) framework, data synthesis was undertaken by comparing and contrasting study participants, methodological designs, study findings, as well as the different types of long-term care (LTC) facilities and country of origin. Details of methods, key outcomes and findings were extracted from primary sources and tabulated to allow for identification of common themes and concepts. Data were grouped according to the research design, sample characteristics, study setting and then coded. A concept map was created after assembling relevant data. After data comparison, similar concepts were regrouped and refined.

### **2.3.5 Description of the studies**

Five qualitative studies were conducted in the USA, four in the UK, three in Canada, two in Ireland, Sweden and China, with the remainder undertaken in the Philippines (1), Switzerland (1), Slovenia (1) and Iran (1). The qualitative traditions represented in the current synthesis of studies were grounded theory (Wilson 1997; Lee *et al.* 2002; Cooney 2012; deGuzman *et al.* 2012; Brandburg *et al.* 2013; Sussman and Dupuis 2014; Stevens *et al.* 2015), phenomenology (Heliker and Scholler-Jaquis 2006; Fraher and Coffey 2011; Hutchinson *et al.* 2011; Johnson and Bibbo 2014; Krizaj *et al.* 2018) and what the authors describe as qualitative design studies (Iwasiw *et al.* 1996; Reed and Payton 1997; Lee 1999; Iwasiw *et al.* 2003; Andersson *et al.* 2005; Lee *et al.* 2013; Zamanzadeh *et al.* 2015; Koppitz *et al.* 2017; Paddock *et al.* 2018). Systematic and integrative literature reviews were undertaken in UK (2), USA (1), Australia (1), China (1) and Netherlands (1) (Lee *et al.* 2001; Brandburg 2007;

Bradshaw *et al.* 2012; Brownie *et al.* 2014; Rijnaard *et al.* 2016; Fitzpatrick and Tzouvara 2018). The only meta-analysis review (Sullivan and Williams 2017) was undertaken in the USA. Five papers were informed by theoretical or conceptual frameworks, namely Meleis's transition theory (Koppitz *et al.* 2017; Sullivan and Williams 2017; Fitzpatrick and Tzouvara 2018); Bridge's transition framework (Brownie *et al.* 2014) and social identity perspective (Paddock *et al.* 2018) (See Appendix 4 for Table of Studies).

### **2.3.6 Participant Characteristics**

The number of participants varied in each study from six older people in both an interpretative phenomenological study (Krizaj *et al.* 2018) and a longitudinal study (Iwasiw *et al.* 2003) to 61 participants in a grounded theory study (Cooney 2012). In all of the 22 studies, the experiences and perceptions of older people were explored. In four studies, family members' perspectives were also investigated (Iwasiw *et al.* 2003; Andersson *et al.* 2005; Zamanzadeh *et al.* 2015; Paddock *et al.* 2018) and one study included staff perspectives (Reed and Payton 1997). Studies were carried out in a range of care homes. Fifteen studies were based in a single care home. Data for the remaining seven studies were drawn from two to six care homes. The timing of data collection varied and ranged from pre-move interviews (Reed and Payton 1997; Krizaj *et al.* 2018) to three days to nine years post the move (Brandburg *et al.* 2013). Six studies interviewed participants on more than one occasion during the first year after the move (Reed and Payton 1997; Wilson 1997; Lee *et al.* 2002; Iwasiw *et al.* 2003; Johnson and Bibbo 2014; Krizaj *et al.* 2018; Paddock *et al.* 2018).

## 2.4 Findings

Four predominant themes emerged from the review: (1) Decision Making and Control, (2) Process of Transition, Adjustment and Adaptation, (3) Psychological Reactions, and (4) Connectedness, Support and Companionship.

### 2.4.1 Decision Making and Control

The lack of participation in decision making and choice about the move to a care home can create a negative experience causing emotional disturbance, isolation, anxiety, uncertainty and personal loss when entering a new environment (Johnson *et al.* 2010; Fraher and Coffey 2011; Lee *et al.* 2013; Zamanzadeh *et al.* 2016; Koopitz *et al.* 2017). A qualitative study undertaken by Iwasiw *et al.* (1996) explored the experiences of newly admitted residents (n=12) in the first two weeks in a long-term care facility following relocation directly from home. Older people's experiences were classified into four categories: emotional reactions, transition activities, reflecting on their situation, and connecting with a personal philosophy. Conditions which appeared to influence their first two-week experiences were being involved in planning for the move, the meanings they attached to the experience and their emotional state. A later study by Iwasiw *et al.* (2003) sought to explore residents (n=6) and family members (n=3) perspectives of the resident's first year in a long-term care facility after relocation from home. Five older people had participated in the decision to move either alone or with a family member. The researchers planned to interview participants at six time points, namely weeks 2 and 6 and then at 3,6,9, and 12 months following the relocation. However, not all participants remained for an entire year and because of the staged approach to recruitment, the total period of data collection was two years. As some participants were unable to remain in the study for the full year,

31 interviews were conducted instead of the originally planned 54 interviews. Six themes emerging from resident and family perspectives were: 1) decision making associated with moving in; 2) fitting in; 3) maintaining previous relationships and establishing new ones; 4) emotional reactions; 5) reflecting on the situation; and 6) maintaining identity, personhood. The majority of residents appraised the long-term care facility negatively, particularly after 3 months. Recognising their vulnerability, older people and their family members stated they were reluctant to voice complaints to staff.

Andersson *et al.* (2005) in their qualitative interviews sought to explore the experiences of older people (n = 13), their relatives (n = 10) and contact persons' (n = 11) experiences of daily life in the care home after admission, with respect to their perceived involvement in the decision to move. Nine residents reported that they were satisfied with living in the care home, most of them almost immediately after their move. Reasons put forward for residents' positive statements included, the nice and competent staff and that 'one becomes safer in a way'. Two of them, however, had found care home living terrible at the beginning. All of the satisfied residents, except one, had participated in the decision to move into the care home. In contrast, three residents reported dissatisfaction with living in a care home. Two of the dissatisfied residents did not find the move desirable, voluntary or legitimate and had difficulty adjusting to living in the care home. Two of these three related that they had not participated in the decision to move.

Fraher and Coffey (2011) undertook a hermeneutic phenomenological study to explore older people's (n=8) experience of the decision to relocate to long-term care

and their early experiences post-relocation. Their findings conveyed that decisions about moving to long-term care were poorly handled, inconsistent, with a lack of choice and involvement in decisions. Although some individuals had anticipated their move, decisions were often made hastily with little or no planning. Individual experiences varied according to the context, history and events that led to the move to the home. Fraher and Coffey concluded that older people accepted and adjusted to their new situation more quickly when the admission was planned.

Sussman and Dupuis (2014), in their grounded theory study of residents (n=10) in three long term care facilities highlighted the ideal stages of a planned admission to a care home environment as: the decision to move, pre-move preparation and moving day circumstances. Residents reported a complex and layered intersection of conditions that shaped their experiences at each stage of the relocation process. When conditions at individual, interpersonal, and/or systemic layers nurtured a sense of control, and respect for personhood, residents reported positive relocation experiences and their ability to develop a sense of comfort and belonging within the long term care facility was facilitated. Conversely, when conditions at one or a series of layers threatened or challenged control and respect for personhood, residents reported negative experiences compromising their subsequent adjustment to long term care.

Some research studies have identified that older people may experience a loss of autonomy and independence making adaptation to life in a care more challenging. Moreover, older people often struggle to adhere to the routine and rules of the care home environment (Wilson 1997; Cooney 2012; Bradshaw 2012; Brandburg *et al.* 2013). There is also evidence to suggest that some care home environments are

restrictive with a lack of privacy, and offer limited opportunity for social interaction, hampered by institutional standardised routines and strict risk management policies that can threaten individuals' independence and autonomy (Cooney 2012; Bradshaw *et al.* 2012; Krizaj *et al.* 2018; Paddock *et al.* 2018). A systematic qualitative review undertaken by Bradshaw *et al.* (2012) examined residents' views of quality of life (QoL), specifically the factors that positively influence care home life. Thematic analysis and meta-ethnographic methods were incorporated into the synthesis of the studies (n=31) identified. Findings revealed that people in care homes voiced concerns about lack of autonomy and difficulty in forming appropriate relationships with others. For a good quality of life in care homes, four key themes were deemed to be necessary: the person's 'acceptance and adaptation to their living situation', their 'connectedness' with others, living in 'a homelike environment' and carers displaying 'caring practices'. This review also supports and extends the finding that a positive approach to living in care homes is associated with effective coping and adaptation.

#### **2.4.2 Process of Transition, Adjustment and Adaptation**

Numerous factors including health and social issues can influence the adaptation and adjustment process for older people when relocating to a care home (Bradshaw *et al.* 2012; Brownie *et al.* 2014; Križaj *et al.* 2018). Furthermore, the 'transition' process has been defined as occurring as a result of change in a person's life continuing until adaptation is reached and producing fundamental changes to an individual's role or identity (Porter and Ganong, 2005; Wiersma and Dupuis 2010; Paddock *et al.* 2018). A grounded theory study undertaken by Wilson (1997) explored variance in the initial responses of older adults (n=15) who moved to a nursing home. Semi structured interviews were undertaken every other day for two weeks, and at one month post-



admission. Data analysis conveyed the transition to nursing home life as occurring in three phases: (1) overwhelmed, (2) adjustment and (3) initial acceptance phase. The major theme of adjusting to nursing home life was protection and maintaining a facade of normalcy. A variance in the process of transition is reported between older adults planned and unplanned admissions to the care home. A planned admission supported an individuals' adjustment better than an unplanned admission. Older people who had not planned the care home admission experienced more emotional responses and a 'desire to go home'.

The transition to a care home represents a uniquely significant experience for older people which was explored within a hermeneutical phenomenology study undertaken by Heliker and Scholler-Jaquish (2006). The researchers describe the phenomenon of being admitted and living in a nursing home from the perspective of ten older residents. Participants were interviewed within one week of admission and then periodically during the next three months. The authors identified three patterns and themes of transition to nursing home living: (1) becoming homeless, (2) getting settled and learning the ropes, becoming known and knowing others and learning the rules and (3) creating a place and making the best of it. The researchers concluded that understanding how residents are grieving their loss of home and may be experiencing an unfamiliar and unknown experience of transition, can lead to innovative practice changes in anticipation of individuals' needs.

In contrast, Brandburg (2007) described three identifiable processes associated with the transition to life in a care home as: 1) the 'initial reaction' or emotional response to the move which is not dependent on whether the admission is planned or unplanned;

2) 'transitional influences' such as life experience and the meaning attached to the relocation and 3) 'adjustment', where the individual comes to terms with the move. The second and third stages, transitional influences, and adjustment, interact and interplay during the process of transition. As a result, older adults are in a dynamic process of adjusting and readjusting as they interact with various transitional influences such as the formation of new relationships with residents and staff. The end of adjustment occurs when the resident comes to terms with living in a care home, has developed new relationships, maintained old friendships, and reflected on their new home environment. According to Brandburg, the final 'acceptance' phase usually occurs between six and twelve months post-admission. This marks the end of the transition period when new residents finally accept living in the nursing home.

Similarly, de Guzman *et al.*'s (2012) grounded theory study explored 20 older people's process of adaptation to the change in their environment, and the emotional transition starting from admission until their acclimatization, in a residential care facility. An 'Hourglass of Acclimatization Model' emerged. This model yielded two distinct phases contributing to successful acclimatization. One is the 'Conversion' phase, the main notion being of transforming one's perspectives of themselves and his or her environment. This is followed by the 'Immersion' phase, which describes how an older person involves him/ herself completely into the life they are supposed to live.

Conversely, a narrative exploration of eight older people's transitions into residential care was undertaken by Lee *et al.* (2013) with a focus on participants who had been living in a residential facility between three and 12 months. Narrative analysis

revealed that the transition process appeared not to be time bound or linear, participants' experiences reflected key plots of 'control', 'power', 'identity' and 'uncertainty' interwoven within individual's daily and more long-term existence. Participants discussed not feeling confident in their decision to move, living in constant fear of losing their memory and having limited expectations for their future. The authors asserted that the emphasis on older people 'accepting' transitions in a 'healthy' way may not encapsulate the reality of how they incorporated relocating to residential care into their narratives. In reality, 'resigned acceptance', previously thought to indicate maladaptive adjustment (Brandburg 2007) appeared more realistic for participants. This study highlighted that transitions can be ongoing, and there is a need to consider broader issues such as identity and maintaining control if they are to fit with residents' life stories.

### **2.4.3 Psychological Reactions**

A major challenge associated with the transition into a care home is the loss of the individual's home life, therefore threatening identity, belonging and sense of self (Lee *et al.* 2013, Brownie *et al.* 2014; Zamanzadeh *et al.* 2015; Paddock *et al.* 2018). Personal resiliency was identified by Brandburg *et al.* (2013) as the key strategy used by participants when making the decision to move into long-term care and in day-to-day living. The experiences and psychosocial effects of transitioning to a care home were explored with older people (n=17) and staff caregivers (n=3) by Zamanzadeh *et al.* (2015). Data analysis of semi-structured interviews categorised the psychosocial effects of transitioning into four themes: communication isolation, resource change, monotone institutional life, and negative emotional response. Participants lost their previous support systems when transitioning and were not able to establish new ones.

Furthermore, routine care was provided by formal caregivers with minimal support and little attention to the needs and desires of individuals to maintain their own independence. These losses gave rise to negative emotions in some of the participants. Personal and environmental factors that facilitated adaptation to relocation were investigated in a phenomenological study undertaken by Hutchinson *et al.* (2011) with older people (n= 23) from six long term care facilities in America. Two tested qualitative instruments, the Life Narrative Interview (Gubrium, 1975/1997) and the Cultural Heritage Interview (Spencer and Hersch 2000) were used to obtain information regarding personal and cultural heritage factors. The themes that emerged included (a) spirituality, death and dying, and philosophy of life; (b) life experiences with change; (c) cultural heritage; (d) health; (e) ethnicity; (f) social support, family and friends; (g) long-term care facility relationships; (h) long-term care facility system maintenance and (i) long-term care facility support of personal growth.

Personal and social identity were also explored within a multiple qualitative case study undertaken by Paddock *et al.* (2018) who investigated how living in a care home affected the identities of residents and how they addressed this in their daily lives. Residents (n=9), relatives (n=4), and staff (n=5) staff took part in semi structured interviews and 260 hours of observations over one year. A data framework analysis, drawing on the social identity perspective as an interpretive lens, was employed. Four themes were identified: (a) changing with age, (b) independence and autonomy, (c) bounded identity, and (d) social comparison. The impact of aging that initially altered residents' identities was exacerbated by the care home environment itself. Institutional restrictions jeopardized autonomy and independence, provoking residents to redefine

this within the allowances of the care home. Moreover, strict routines and resource constraints resulted in the bounded expression of personalities.

In adapting to new surroundings, the importance of bringing a sense of home and possessions to the care home environment has been highlighted, which can have a significant psychological and emotional impact (Marshall and McKenzie 2008; Cooney 2012; Falk *et al.* 2012). The factors that impact on residents' transition and psychological adaptation to long-term care facilities was explored in a systematic literature review by Brownie *et al.* (2014), informed by the concept of home, and Bridges' (2004) three stages of transition. This framework provided conceptual models for understanding the needs and aspirations of older people who are in the process of this late life transition. The authors identified 19 observational, descriptive, and cross-sectional studies exploring older people's views about their experiences relocating and adjusting to life in a care home. Positive adaptation was reported to be influenced by older people being able to retain personal possessions, continue valued social relationships and establish new relationships within the care facility.

The importance of connectedness to others is also highlighted in an Interpretative Phenomenological Analysis (IPA) study undertaken by Krizaj *et al.* (2018) that explored six older people's experiences of transition into a care home and how it influenced their everyday engagement in meaningful occupations. Semi structured interviews were conducted at three time intervals: before the relocation, and at one month and six months after the relocation into a care home. Overarching themes developed from interviews were: 'Holding on to what I do,' 'The significance of others through transition', and 'The time of loss and acceptance'. The transition was

seen as a challenging continuous process with older people striving to maintain their identities through engaging in their previously enjoyed occupations.

Meleis's theory of transitions explains how a person relates to their environment and health. A change in health and environment can change how a person perceives his/her role. Furthermore, an individual's response to change can be influenced by internal (attitude, knowledge, cultural beliefs) and external factors (social support, socioeconomic status) (Meleis, 2010). A qualitative metasynthesis undertaken by Sullivan and Williams' (2017) reviewed eight studies of older adults' transition experiences to long-term care facilities. The synthesis of the literature was guided by Meleis's middle range theory of transition (MMRTT) which consists of types and patterns of transitions, properties of transition experiences, facilitating and inhibiting conditions, process indicators, outcome indicators, and nursing therapeutics (Meleis *et al.* 2000). Three themes were uncovered by this meta-synthesis: (a) painful loss that requires a mourning process, (b) seeking stability through gaining autonomy to sustain a new sense of self, and (c) acceptance, when a unique inner balance is reached. The study findings suggest that residents transitioning to long term care experience an inevitable loss; therefore, mourning the loss is necessary to progress through the transition. Residents expressed a longing for home related to having autonomy, privacy, and activities that provide personal meaning; they wanted to be known and valued for who they are and what they have achieved in life.

A narrative synthesis conducted by Fitzpatrick and Tzouvara (2018) also informed by Meleis's Theory of Transition sought to understand what factors facilitate and inhibit the transition for older people who have relocated to a long-term care facility. Thirty-

four studies (25 qualitative, 7 quantitative and 2 mixed methods) met the inclusion criteria. Data synthesis conveyed the transition following relocation, as being examined using a variety of terms, timelines, and study designs. Potential personal and community focused facilitators and inhibitors were mapped to four themes: (1) resilience of the older person, (2) interpersonal connections and relationships, (3) this is my new home, and (4) the care facility as an organisation. Within the theme of 'resilience of the older person', person-focused transition facilitators included self-efficacy, self-determined motivation, continuation of one's faith, values and beliefs, ethnic identity, a positive personal philosophy, and personal coping strategies. The authors concluded that these findings could inform the development of interventions to support change in these identified areas. They also emphasise that further research is warranted to understand how the culture of long-term care facilities can influence older people's transition and how this might be moulded to create and sustain a more caring culture for older people.

#### **2.4.4 Connectedness, Support and Companionship**

A major challenge associated with the transition into a care home is the loss of the individual's home, therefore threatening identity, belonging and sense of self (Lee *et al.* 2013; Brownie *et al.* 2014; Fitzpatrick *et al.* 2018; Paddock *et al.* 2018). Home is not only fundamental to a person's self-identity and social relationships, but homely environments are essential to promote recovery, well-being, and quality of life (Molony 2010; Rioux and Werner 2011; Bokerman *et al.* 2012). Additionally, individuals may lose previous social and communication networks (Zamanzadeh *et al.* 2016) putting them at risk of feeling lonely and isolated (Brownie *et al.* 2014). A qualitative study undertaken by Reed and Payton (1997) examined the processes of

adaptation older people engage in when moving into care homes. The authors found that theoretical categories crossed over several topics, such as the 'settling in' processes and involved a range of different dimensions, ranging from the physical environment to interpersonal relationships. The disparity between the views of residents and staff suggested that the importance of other residents' support and companionship, is poorly understood by staff.

A grounded theory study undertaken by Cooney (2012) explored older peoples' perceptions of 'being at home' in long-term care settings and the factors that influence these perceptions. Residents (n = 61) living in four types of long-term care facilities, aged 65-90 were interviewed either after admission or had lived in the long term care facility for longer than three months. Four categories were identified as critical to finding a home in long-term care settings: 'continuity', 'preserving personal identity', 'belonging' and 'being active and working'. 'Finding Home' was conceptualised as the core category. The potential to 'find home' was influenced by mediating and facilitating/ constraining factors. What made it simpler or more problematic for older people to 'find home' was either unique to the individual (adaptive responses, expectations and/or past experiences) or occurred at an institutional level (ethos of care, institutional culture, environment of setting). The Theory of Finding Home describes the factors central to 'finding home' in long-term care settings and identifies how nurses can support residents to feel at home. Comparably, a grounded theory study undertaken by Falk *et al.* (2012) aimed to gain a deeper understanding of the processes and strategies used by older people (n=25) to create a sense of home, place-attachment and privacy in residential care facilities. Findings showed that a sense of home in residential care involves strategies related to three dimensions of the



environment: (1) attachment to place, (2) to space and (3) attachment beyond the institution. The authors conclude that the circumstances under which older people manage or fail in creating attachment, consist of psychosocial processes involving both individual and shared attitudes and beliefs.

Rijnaard *et al.* (2016) undertook a systematic review of seventeen mainly qualitative research studies to provide an overview of factors influencing the ‘sense of home’ of older adults residing in the nursing home. The ‘sense of home’ of nursing home residents was influenced by 15 factors, divided into three themes: (1) psychological factors (sense of acknowledgement, preservation of one’s habits and values, autonomy and control, and coping); (2) social factors (interaction and relationship with staff, residents, family and friends, and pets, and activities); and (3) the built environment (private space and (quasi-) public space, personal belongings, technology, look and feel, and the outdoors and location). Rijnaard *et al.* suggested further research to determine if and how the identified factors are interrelated, if perspectives of stakeholders involved vary, and how the factors can be improved in practice.

## **2.5 Synopsis of study findings**

The findings of this literature review suggest that lack of participation in decision making and choice about the move to a care home can create a negative experience for some individuals causing emotional disturbance including anxiety, uncertainty, isolation, and personal loss (Johnson *et al.* 2010; Fraher and Coffey 2011; Lee *et al.* 2013; Brownie *et al.* 2014; Zamanzadeh *et al.* 2016; Koopitz *et al.* 2017). The extent to which individuals can exercise control over the decision to move to a care home is

recognised as an important determinant of their relocation experience (Andersson *et al.* 2005; Johnson *et al.* 2010; Fraher and Coffey 2011; Lee *et al.* 2013; Sussman and Dupuis 2014; Ryan and McKenna 2015; Stevens *et al.* 2015; Paddock *et al.* 2018). The review also suggests that good communication can enhance the move for residents and families, allowing them to feel confident in their decisions, enabling them to ask questions and make suggestions without fear of repercussions. On the other hand, poor communication leads to uncertainty, worry and anxiety (Ellis, 2010; Cooney 2012; Falk *et al.* 2012; Graneheim *et al.* 2014; Ryan and McKenna 2015; Sullivan and Williams 2017).

It has been recognised that numerous complex and multidimensional factors including health and social care issues can influence the adaption and adjustment process for older people when relocating to a care home (Reed and Payton 1997; Wilson 1997; Lee *et al.* 2002; Bradshaw *et al.* 2012; de Guzman *et al.* 2012; Brownie *et al.* 2014; Koppitz *et al.* 2017; Moore and Ryan 2017; Sullivan and Williams 2017; Krizaj *et al.* 2018; Paddock *et al.* 2018). The need to ‘learn the ropes’ is reported as an additional source of stress and anxiety for some individuals (Wilson 1997; Heliker and Scholler-Jaquish 2006). However, there is evidence to suggest that a positive approach to living in a care home is associated with effective coping and adaptation (Bradshaw *et al.* 2012; Sullivan and Willis 2018).

Several studies have indicated that leaving home and being separated from family and communities can compound feelings of loss and isolation (Iwasiw *et al.* 1996; Heliker and Scholler-Jaquish 2006; Fraher and Coffey 2011; Hutchinson *et al.* 2011). It has also been recognised that when independence is removed from a person’s life, an

individual can feel defeated, depressed, or begin to doubt their own ability to care for themselves (Wiersma and Dupuis 2010; Custers *et al.* 2012). Furthermore, low expectations can lead to reduced capabilities and can be self-fulfilling, causing deterioration in health and cognitive ability (Lee *et al.* 2013; Zamanzadeh *et al.* 2016). Therefore, maintaining continuity between the older person's past and present role has been identified as an important factor in the adaptation process after entry to a care home (Bradshaw *et al.* 2012; Brownie *et al.* 2014; Krizaj *et al.* 2018).

A major challenge associated with the transition into a care home is the loss of the individual's home, therefore threatening identity, belonging and sense of self (Lee *et al.* 2013; Brownie *et al.* 2014; Paddock *et al.* 2018). Research has identified that following care home admission individuals can lose their previous social networks and are unable to create new ones (Zamanzadeh *et al.* 2016) and are at risk of feeling lonely and isolated (Brownie *et al.* 2014). Maintaining continuity between the older person's past and present role has been identified as a key factor in the adaptation process after entry to a care home (Bradshaw *et al.* 2012; Falk *et al.* 2012; Brownie *et al.* 2014; Krizaj *et al.* 2018). There is evidence to suggest that individuals may experience a greater sense of freedom; be able to regain some of their independence and feel less of a burden to others (Bradshaw *et al.* 2012; Sullivan and Williams 2018). Moreover, it is recognised that care staff have an important role to play in encouraging new residents to develop new relationships (Cooney 2012; Krizaj *et al.* 2018).

## **2.6 Conclusions**

Within the current body of literature there is a lack of detailed understanding of the processes older people undergo that describe their experiences during the day to day

adjustment and adaptation to living in a care home. Furthermore, there is limited research into the psychological and/or social experiences of older people moving into a care home that takes into consideration the total relocation process, incorporating residents' early and ongoing experiences during the transition. The development of a comprehensive body of knowledge of older people' adjustment and adaptation to a care home has the potential to identify relevant social and health care practices that can facilitate adaptation. This literature review has identified that there is a significant dearth of studies not only of the [pre-move](#) experiences of the older person' moving to a care home, but there are also limited studies undertaken within the initial weeks and months following the move. The identified studies are also associated with small sample sizes. Significantly, there has not been a study identified that has followed participants' transition from their own home to a care home over a one year period. The purpose of gathering data over a prolonged period is to elucidate the ways in which older people cope with the many changes associated with the move to a care home, for example, leaving their home and being separated from family, friends and communities. The way in which individuals are supported (or not), may have a bearing on their ongoing adaptation to life in the care home.

## **2.7 Chapter Summary**

This chapter has presented an integrative literature review exploring the transition of older people to a care home environment. Four predominant themes emerged from the review: (1) Decision Making and Control, (2) Process of Transition, Adjustment and Adaptation, (3) Psychological Reactions, and (4) Connectedness, Support and Companionship. The literature review identified that there is a dearth of research on the extent to which residents can be facilitated to feel 'at home' in a care home

environment, particularly during the first year of the move. This study seeks to address this imbalance. The next chapter will present a critical appraisal of grounded theory and the rationale for choosing a grounded theory methodology.

## **CHAPTER THREE:**

### **METHODOLOGY**

#### **3.1 Introduction**

The previous chapter provided an integrative literature review exploring the experiences and perceptions of older people during the transition from living at home to living in a care home. The aim of this chapter is to focus on the choice of research design and methods within this qualitative study. The first section will present a critical appraisal and the philosophical underpinnings of grounded theory. The second section includes the rationale for choosing a grounded theory approach and its application to the study. In the third section an outline of recruitment and sampling selection is presented, followed by ethical considerations, data collection, analysis, rigour, and discussion on the methods employed to ensure credibility of the study's findings. Further details regarding theoretical sampling, data collection and analysis pertaining to each time point of data collection are provided within chapter four.

#### **3.2 Research Aim**

Consistent with a grounded theory methodology, the broad aim of this research study was to explore older people's experiences of moving from home to a care home over four time points during the first year of the move.

#### **Broad Research Objectives:**

- To explore participants' perceptions of the circumstances surrounding the decision to move to a care home.

- To explore the factors influencing participants' experiences of the first year of their transition to life in a care home.
- To develop a substantive theory contributing to our understanding of the factors supporting a better transition from living at home to living in a care home.

The study was designed to gain an insight into the ways in which older people adapt to life in a care home with a particular focus on critical time periods during the first year of the move. These were before (or immediately after the move), the 4-6 week period after the move, the 4-5 month period after the move, and finally the 9 and 12 month period after the move. These time frames were important for the following reasons: (i) there are very few studies that have explored older peoples' experiences of transition to a care home pre-move and in the 4-6 week period post relocation; (ii) the 5 month inclusion criterion was important as this was consistent with the time frame for confirmation of permanent residency; and (iii) there are no known studies that have followed the same group of participants over the course of a year.

### **3.3 Philosophical underpinnings of ontology, epistemology, and methodology**

A researcher takes a certain philosophical stance in order to answer questions regarding ontology, epistemology, and methodology (Denzin and Lincoln 2008). Historically, the most frequently used paradigm has been objectivism, taking a positivist standpoint. This paradigm is connected to empirical science asserting to being objectively proven and the notion that truth can be discovered (Crotty 1998). However, it has now been recognised that a positivist approach is not deemed

appropriate for all research questions. Therefore, diverse philosophical positions have informed a range of methodologies including post-positivism, constructivism, and emancipatory approaches (Denzin and Lincoln 2008; Polit and Beck 2012). The philosophical study of being, ontology, considers existence and questions what constitutes reality. Thus, the researcher's ontological stance is reflected in how one views the world and the nature of how that reality is influential in shaping the search for understanding. Epistemology on the other hand considers how knowledge is created and how we learn about our world. Both ontology and epistemology are key considerations in determining how the search for understanding is conducted (Creswell 2014). Researchers are required to select an appropriate paradigm for the phenomenon to be studied (Parahoo 2014). As the focus of this study was an in-depth exploration of older people's experiences of moving from home to a care home, an interpretive research paradigm methodology was deemed to be the most appropriate. Interpretive research is a research paradigm based on the assumption that social reality is not singular or objective but rather, is influenced by human experiences and social contexts (ontology), and is consequently best studied within its socio-historic context by reconciling the subjective interpretations of its various participants (epistemology) (Lincoln and Guba 2000).

### **3.4 Choosing a research design**

Regardless of philosophical underpinnings, research by nature is systematic and rigorous. It is about a carefully considered search for truth (Houser 2013), with an overall plan for addressing a research question, including strategies for enhancing the study's integrity (Polit and Beck 2012). A significant discourse takes place within the literature about the variances between inductive enquiry and deductive enquiry, the



former more aligned to qualitative and the latter more aligned to quantitative (Polit and Beck 2012; Parahoo 2014). While a distinction between positivist and interpretivist research happens at the paradigm level, each methodology has explicit criteria for the collection, analysis, and interpretation of data (Creswell 2013). Furthermore, in order for a study to be methodologically coherent, researchers must be aware of the philosophical assumptions underpinning their research and choose the most appropriate methods to achieve their proposed research aims (Mayan 2009; Bryman 2012).

Historically, qualitative research has been employed in fields such as sociology, history, and anthropology. Moreover, qualitative data have potential to be a source of well-grounded, rich descriptions and explanations of processes in identifiable local contexts (Miles and Huberman 2009). Qualitative research has been reported by Flick (2014) to be concerned with analysing subjective meaning or the social production of issues, events, or practices by collecting non-standardised data and analysing texts and images rather than number and statistics. Furthermore, Denzin and Lincoln (2008) state that qualitative research is multi-method encompassing an interpretive, naturalistic approach to its subject matter. Essentially, qualitative research facilitates the researcher to discover the participants' inner experience, and to consider how meanings are developed (Corbin and Strauss 2008).

There are five qualitative research traditions as espoused by Creswell (2009) which are (a) ethnography, (b) grounded theory, (c) case study, (d) phenomenology, and (e) narrative. Each of these five traditions observe a specific methodology based upon how the researcher explains their ontology, epistemology, and axiology. Within this

study phenomenology and grounded theory methodologies were given due consideration and attention to address the research question.

Phenomenology can be defined as an approach to research that seeks to describe the essence of a phenomenon by exploring it from the perspective of those who have experienced it (Creswell 2013). The focus is not on the participants themselves or the world that they inhabit, but rather on the meaning or essence of the interrelationship between the two (Merriam and Tisdell 2015). Having sought information on phenomenology by consulting relevant literature and reading research studies, a phenomenological approach to explore how older people make the transition from home to long term care was initially considered. A phenomenological approach that centred on accessing and interpreting the subjective lived experiences of the individual could deliver the in-depth experience, description and understanding of these experiences. However, the present study concerned the processes and interactional aspects associated with older people's transition to long term care, and in the context of selecting a methodology with some degree of explanatory capability, phenomenology was not deemed to be the most appropriate option.

A grounded theory approach, consistent with the work of Strauss and Corbin (1990, 1998), was chosen for this study as it facilitated the development of a new perspective on the experiences of older people moving from home to a care home with a particular focus on their first year of life in a care home. The aim of grounded theory research is to explore social processes or situations to which people must interact and adapt (Benoliel 1996; Schreiber 2001; Charmaz 2006; Corbin and Strauss 2008; Morse *et al.* 2009; Maz 2013). As an exploratory method, grounded theory is particularly well

suited to investigate social processes that have received limited research attention, where the previous research is lacking in breadth and/or depth, or where a new point of view on familiar matters seem promising (Milliken 2010). Moreover, grounded theory is an ideal methodology to understand actions and processes through transitions (Morse 2009). The justification for using a grounded theory design is that the transition to care home life is a complex social process with individuals experiencing many psychological and/or social changes over time. Moreover, it is a field in which constant change is happening and the research ground is not yet extensively mapped.

### **3.5 Philosophical underpinnings of grounded theory**

Grounded theory originated in the mid-1960s with the pioneering work in medical sociology of Barney Glaser and Anselm Strauss who collaborated in a research study to examine awareness of dying. During this research, Glaser and Strauss encountered and criticised the "overemphasis" of verifying theories to the detriment of essentially generating the theory itself (Glaser and Strauss 1967; Morse 2009). They asserted that the dual process of generating and verifying a theory should receive equal treatment within social research. Hence in 1967, after the completion of *Awareness of Dying* came the subsequent publication 'The Discovery of Grounded Theory' (Glaser and Strauss 1967).

Grounded theory has its origins in interpretivism, which concentrates on the way people make sense of their reality. One area of interpretivism is symbolic interactionism, which describes how people act, interact, and adapt in their daily lives (Holloway and Galvin 2017). Moreover, an important aspect of symbolic interactionism is that individuals cannot be separated from the contexts in which they

exist (Handberg, *et al.* 2015). As Glaser and Strauss continued to establish and develop grounded theory, their progression introduced professional and methodological divergence. During the 1970's and 80's Glaser and Strauss published their work distinctly rather than collaboratively (Glaser 1978; Strauss 1987) and discontinued their professional collaboration.

Grounded theory is an inductive research methodology. The central components of grounded theory are data collection, coding, analysis, memo writing, and theoretical categorisation (Glaser 1992). Glaser is generally recognised as having retained both the spirit and the substance of the original work (Glaser 1978; 1992; 1998; Locke 2001). Conversely, by 1990 Strauss had established an academic association with Juliet Corbin and together they refined particular features of the original (classic) grounded theory (Strauss and Corbin 1990; 1998). Strauss and Corbin revised the original principle of the natural emergence of a theory from data, to be discovered by the researcher. Instead, they developed an analytical and prescriptive framework for coding, intended to deduce theory from data systematically, interpretive grounded theory (IGT).

This rigorous coding framework emphasised the philosophy of pragmatism and symbolic interactionism. Grounded theory examines the “Six Cs” of social processes (causes, contexts, contingencies, consequences, covariances, and conditions) to understand the patterns and relationships among these elements (Strauss and Corbin 1998). According to Strauss and Corbin (1998, p. 12):

*.... grounded theory is derived from data, systematically gathered, and analysed through the research process. In this method, data*

*collection, analysis and eventual theory stand in close relationship to one another. A researcher does not begin a project with a preconceived theory in mind (unless his or her purpose is to elaborate and extend existing theory). Rather, the researcher begins with an area of study and allows the theory to emerge from the data.*

Strauss and Corbin continued to work together developing interpretive grounded theory until Anselm Strauss died in 1996. Strauss (posthumous) and Corbin's most recent publication includes a reflection on how far IGT has developed (Corbin and Strauss 2015). A contemporary grounded theorist Kathy Charmaz, a student of Glaser and Strauss affirms that constructivist grounded theory (CGT) is a revision of Glaser and Strauss's (1967) and Glaser's (1978) classic grounded theory. Charmaz asserts that CGT assumes a relativist epistemology, seeing knowledge as socially produced, acknowledges multiple standpoints of both the research participants and the researcher, and takes a reflective stance towards our actions, situations and participants in the field setting and the researchers' analytical constructions of them (Charmaz 2008).

Glaser and Strauss (1967) considered it important for their methodology (identified as the constant comparative method or constant comparative analysis), to 'fit and work'; namely, to have the conceptual power to explain and predict. By 'fit', in the context of grounded theory, Glaser and Strauss (1967) referred to the need for conceptual categories to be applicable to the data under study. The meticulous application of essential grounded theory methods refines the analysis resulting in the generation of an integrated, comprehensive grounded theory which explains a process relating to a particular phenomenon (Birks and Mills 2015).

The findings of a grounded theory study are presented as a set of interrelated and whole concepts, articulated in the production of a substantive theory (Glaser and Strauss 1967). A substantive theory therefore is a theoretical interpretation or description of a studied phenomenon (Bryant and Charmaz 2007; Birks and Mills 2015). In this study, grounded theory methodology consistent with the work of Strauss and Corbin (1998) was chosen, because the methodological processes are clearly outlined with specific guidelines for data analysis which are both prescriptive and structured. As a doctoral level researcher, new to grounded theory, the guidelines and framework offered by Strauss and Corbin provided a concrete direction and suited the focus of the study and matched personal values as a researcher.

### **3.6 Constant comparative analysis in grounded theory**

The constant comparative analysis method is a core feature of grounded theory and is an iterative and inductive process of reducing the data through constant recoding (Glaser and Strauss 1967). Constant comparative methodology incorporates four stages: “(1) comparing incidents applicable to each category, (2) integrating categories and their properties, (3) delimiting the theory, and (4) writing the theory” (Glaser and Strauss 1967, p. 105). During the four stages of the constant comparative analysis, the researcher constantly organises the data collection, undertakes analysis and codes the information, and reinforces theory generation through the process of theoretical sampling. Constant comparisons are made of similar or different instances in the data collected.

*.... In contrast to analytical induction, the constant comparative method is concerned with generating and plausibly suggesting (but not provisionally testing) many categories, properties, and hypotheses about general problems. Some of these properties may be causes, as in analytical induction, but unlike analytical induction others are conditions, consequences, dimensions, types, processes etc.*

(Glaser and Strauss 1967, p. 104)

According to Corbin and Strauss (2008), there are two types of comparison creating, the first is constant comparative analysis and the second is the making of theoretical comparisons. Constant comparative analysis correlates with the simultaneous collection, coding, and analysis of data, where every item of data is compared with every other piece. Ongoing data collection is analysed for any evident comparisons and similarities. Emerging incident similarities are categorised accordingly and continuously evaluated for similar contextual elements. In the context of constant comparative analysis, the preparation of memos is another feature that prevails, regardless of the methodological perspective of grounded theory (Kenny and Fourie 2014). Memos feature why and how decisions are formulated connected to sampling, coding, collapsing of codes, establishing new codes, separating codes, producing a category, and identifying relationships conceptualised to a higher level of analysis (Birks and Mills 2015). Moreover, theoretical sampling together with constant comparative analysis raises the conceptual levels of data analysis and steers ongoing data collection or generation (Birks and Mills 2015).

### **3.7 Theoretical sampling in grounded theory**

Theoretical sampling is a core process of grounded theory, with the study sample size not being pre-determined in advance of data collection. This method of sampling is dependent on the developing concepts within data collection and analysis to direct

with whom, how and where, additional data should be collected to develop a theory (Glaser and Strauss 1967; Corbin and Strauss 2008; Corbin and Strauss 2015). While research studies often commence by sampling for a measure of heterogeneity or purposeful sampling (Morse 2007), theoretical sampling can begin in the early phases of a study to gain a better grasp of the characteristics and possible variation of categories and concepts that are emerging in the data. Theoretical sampling has been defined as:

*.... The process of data collection for generating theory whereby the analysts jointly collect, codes, and analyses his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges.*

(Glaser and Strauss 1967, p. 45)

While Strauss and Corbin (1998) proposed that purposive sampling might be pragmatically justifiable, they preserve an iterative, theoretically driven creativity:

*Theoretical sampling begins after the first analytic session and continues throughout the research process*

(Corbin and Strauss 2008, p. 149)

Corbin and Strauss (2008) identified two questions that should be addressed within theoretical sampling. One relates to its benefits over other methods of sampling and the other pertains to how best to move forward with theoretical sampling. Corbin and Strauss (2008) advocated that attaining data saturation is equally simple and complex. Simple, in that data is accumulated to the point of 'saturation', when no new concepts are emerging. Complex in the sense that attaining data saturation is not always easily achieved. An interrogative approach throughout data collection processes enables the



researcher to continue collecting and analysing this data until 'saturation' is achieved. Data saturation is achieved when key categories with depth and variation in terms of their development emerge. Corbin and Strauss (2008) advised that complete saturation is possibly never achieved, most researchers will continue with the process of data collection and analysis until they sense that they have accomplished this state.

While having had some previous experience of being involved in determining the sample size of a research study, employing grounded theory as a methodology was relatively new. Similarly, personal knowledge and experience of managing a care home was not comparable to the unique experiences of the individuals making the move to a care home. Therefore, theoretical sampling was deemed to be an appropriate approach, principally because the emerging theory is resolutely grounded in data derived from individuals, whose knowledge and experience is central to the process.

### **3.8 Theoretical sensitivity in grounded theory**

Theoretical sensitivity relates to the researcher's insight and ability to give meaning to data. This is achieved by understanding and deciphering the relevance of the data, and that codes and categories are grounded in the data as opposed to being introduced from previous perceptions. Being theoretically sensitive and expending insight, enables the researcher to develop a theory that is grounded, theoretically dense, and cohesive (Glaser 1978). Conversely, Strauss and Corbin (1990) purport that theoretical sensitivity can come from several sources including (1) literature, in depth reading offers a rich understanding of the phenomena being studied; (2) professional and personal experience which offers an understanding of the events and topics being

explored; and (3) the analytic process itself which allows for insight and understanding of the phenomena.

Corbin and Strauss (2015, p. 78) describe sensitivity as “having insights as well as being tuned into and being able to pick up on relevant issues, events, and happenings during collection and analysis of the data”. In order to develop theoretical sensitivity, the researcher needs to be competent in interpreting and assigning meaning to data while safeguarding against trying to develop hypotheses prematurely through data verification, rather than trying to build theory from data (Urquhart *et al.* 2010).

The use of literature, as a source of data and its impact on theoretical sensitivity, has received considerable attention in grounded theory. Academics continue to debate how extensive and at what stage of the research process the literature review should be undertaken (Tappen 2011; Polit and Beck 2012; Saks and Allsop 2013). Two perspectives about the timing of the literature review in grounded theory are evident in the literature. Glaser (1992) advocated that the literature review should be delayed until after the empirical data collection, then literature could be used as ‘data’ and constantly compared with the emerging categories to be integrated in the theory and used to inform the researcher’s analysis rather than to direct it. Conversely, Strauss (1987), promoted extensive reading in related topics while delaying reading in the substantive subject area until after the data collection.

Although every effort was made to remain theoretically sensitive to the data, the influence of past care experiences and accumulated knowledge cannot be underestimated. This included postponing a comprehensive review of the literature

until data collection was complete as this helped to maintain a degree of sensitivity, as did extensive discussions with supervisors and work colleagues.

### **3.9 Addressing disparities within grounded theory**

The grounded theory initially formulated by Glaser and Strauss (1967) has several distinct methodological forms: traditional grounded theory associated with Glaser; evolved grounded theory associated with Strauss, Corbin and Clarke; and a constructivist grounded theory associated with Charmaz (Bryant and Charmaz 2007; Birks and Mills 2015; Polit and Beck 2017).

The various grounded theory approaches have a recognisable set of ‘family resemblances’ (Bryant and Charmaz 2007b, p. 11) that are hallmarks of a grounded theory study. Key characteristics (see Table 3.1) include that grounded theory elucidates a process; commences with inductive logic; incorporates simultaneous data collection, analysis, and theory construction; encompasses constant comparison and memo writing; utilises theoretical sampling; and focuses on the creation of a grounded theory (Glaser and Strauss 1967; Charmaz 2006; Corbin 2009; Corbin and Strauss 2015).

Although there are identifiable grounded theory characteristics, there are also noteworthy differences between the approaches. The main epistemological and methodological differences between the approaches of Glaser, Strauss, and Corbin and Charmaz have been summarised in Table 3.1 (Adapted from, Sebastian 2019).

The grounded theory approach that was used in this study is consistent with the original work by Glaser and Strauss (1967) and Strauss and Corbin (1998). While the use of literature and emphasis on theoretical sensitivity is more consistent with a Glaserian approach, the analysis of data and use of the paradigm model are evidently more aligned with Strauss and Corbin.

**Table 3.1:** *Main epistemological and methodological differences between Glaser's, Strauss and Corbin's and Charmaz's approaches to grounded theory (Adapted table from Sebastian, 2019)*

	<b>Classic Grounded Theory (Glaser)</b>	<b>Interpretive Grounded Theory (Strauss and Corbin)</b>	<b>Constructivist Grounded Theory (Charmaz)</b>
<b>Epistemology</b>	Critical realist ontology and a post-positivistic paradigm.	Social constructivist and post-structuralism or post-modern paradigm.	Positivist-constructivist continuum
<b>Philosophical Influence</b>	Attempts to be free from influence.	Interpretivism	Constructivism
<b>Researcher' Role</b>	The researcher is to remain distant and detached	The researcher is engaged and actively interprets the data	The researcher constructs rather than discovers
<b>Literature Review</b>	To be undertaken following data analysis.	Permitted prior and during the data collection process. Can be used for data comparisons and to enhance sensitivity.	There is no set time. It is up to the researcher' decision making process. If written early, it should be revisited to critique and confirm the research conclusion.
<b>Research Question</b>	There should be no determined. Questions should appear during data analysis.	Kept vague for flexibility becoming clearer as data emerges.	Influences how data is collected. Should be altered if more key questions arise.

<b>Data Coding and Analysis</b>	(a) Substantive Coding (b) Theoretical coding Focuses on patterns or trends within the data. Includes comparative method and use of a core category. Includes Theoretical coding to merge categories together into a substantive theory.	(a) Open Coding (b) Axial Coding: using the paradigm model. (c) Selective Coding allows for single occurrences within data to be coded and analysed for significance. Constant comparative method and use of core category Rebuilding categories to be more significant and develop a substantive theory.	(a) code everything (b) group all data around the most predominant codes (includes focused coding). Allowance of more than one core category
<b>Theory creation and Verification</b>	Distinct separation between theory generation and verification. Creation of a substantive or formal theory. Verification can only occur by quantitative analysis.	Creation of a substantive or formal theory is central. Verification occurs through multiple perspectives confirming the same data.	Constructed theory is an interpretation rather than an exact representation which is dependent on researchers view.

The way in which disparities in grounded theory are addressed in this study are highlighted in more detail below with a focus on key areas including research questions, sampling, data analysis and rigour.

i. Research question

In their earliest work, Glaser and Strauss (1967) reasoned that theoretical concepts and hypothesis must only emerge from the data. Conversely over time, both authors reviewed their judgment on this aspect of grounded theory. In 1992, Glaser revised

his earlier opinion and asserted that research questions cannot be articulated prior to data collection and must arise from the data. Strauss and Corbin (1990) on the other hand, recognised that researchers need an initial research question in order to focus their attention upon the particular phenomenon they wish to investigate (Strauss and Corbin, 1990). The initial research question should serve to identify, but not make assumptions about the phenomenon of interest.

Consequently, while the literature on the subject was not formally reviewed, previous knowledge and experience in this area of investigation could not discount the potential influence this had on the proposed study. Moreover, in developing a research proposal for funding and ethical approval, it would have been challenging to persuade research ethics committee members and funders, that research questions were not necessary. Therefore, Strauss and Corbin's (1998) approach was employed. A number of questions as a means of structuring and focusing the research study were developed (Appendix 5) and these were subsequently amended and refined as the study progressed.

## ii. Sampling

Theoretical sampling is a central tenet of classic grounded theory and is essential to the development and refinement of a theory that is 'grounded' in data. The crucial principle is to generate sufficient data so that revealing patterns, concepts, categories, properties, and dimensions of the particular phenomena can emerge (Glaser and Strauss 1967; Strauss and Corbin 1998).

The theoretical sampling procedure decrees the researcher to select participants who have experienced or are experiencing the phenomenon under study. Thus, the researcher chooses ‘experts’ in the phenomenon who are therefore equipped to provide the best data (Glaser and Strauss 1967; Corbin and Strauss 1998). The process of selecting participants is a developing process based on the evolving patterns, categories and dimensions emerging from the data. Glaser’s (1998) thinking in relation to theoretical sampling was that events and sites are chosen after data collection has commenced with the intention of develop the emerging theory. In contrast Strauss and Corbin (1990, 1998) contended that sites and events may be chosen prior to data collection through purposive sampling. Corbin and Strauss (2008) further stress that in undertaking theoretical sampling, researchers should ensure that the research is guided by analysis. This process needs researchers “to ask questions and then look to the best source of data to find the answers to the questions” (Corbin and Strauss 2008, p. 146). An important question in attaining closure is when to stop sampling. Glaser (1992) proposes that researchers should stop sampling when theoretical saturation is reached. Theoretical saturation is the stage at which incremental learning is minimal because the researcher is observing phenomena they have already seen before (Glaser and Strauss 1967).

Both Glaser and Strauss (1967) and Strauss and Corbin (1998), advised that the appropriate sample size for a grounded theory study could be answered by the concept of ‘theoretical saturation’. Theoretical saturation occurs in data collection when:

*(a) no new or relevant data seem to emerge regarding a category, (b) the category is well developed in terms of its properties and dimensions demonstrating variation, and (c) the relationships among categories are well established and validated.*

(Strauss and Corbin 1998, p. 212)

As part of the research study, an ethical approval application had to be submitted. In addition, a research scholarship was applied for. These applications would have proved difficult without some reference to sample size and selection. In addition, Ulster University's Research Ethical Committee sought specific details about sampling issues and procedures for working with a vulnerable population. Therefore, purposive sampling consistent with Strauss and Corbin (1998), was the initial approach used in the study. Thereafter, theoretical sampling was employed.

### iii. Data analysis

Significant differences between grounded theory methodology are evident in the approaches to coding, specifically, in the degree of researcher involvement and at what time (Evans, 2013). These variances have stirred a debate about permitting data to emerge, as opposed to forcing the data within a predetermined framework. Glaser asserted that classic grounded theory alone permits theory to emerge since it has no external frame until theoretical coding is conducted (Glaser, 1978). He suggested that deduction and hypotheses verification should be left for quantitative researchers, which is apparent in this statement from Glaser and Strauss (1967, p. 28).

*'Comparative analysis both subsumes and assumes verification and accurate description, but only to the extent that the latter are in the services of generation' Although they view constant comparison as incorporating verification, it is only used within the primary processes of induction and generation of theoretical ideas.*

Conversely, Strauss and Corbin (1990) suggested the use of existing social structures as core categories and not the coding family as espoused by Glaser (1992).



Consequently, Glaser accused Strauss and Corbin (1990) of forcing data rather than allowing it to emerge. Despite these contentions, Corbin and Strauss (2008) proposed a model to follow that can assist the researcher. For the purpose of this study, Corbin and Strauss's (2008) paradigm model framework was utilised for transparency of coding and analysis and enhanced the credibility and trustworthiness of the findings, thus establishing rigour. The paradigm model is discussed in more detail in section 3.21 of this chapter.

#### iv. Rigour

According to Glaser, the essential requisites for denoting the quality of a grounded theory study are:

*(1) the significance of the researcher getting out into the field to understand what is going on, (2) the importance of theory which is grounded in reality, (3) the nature and significance of experience in the field for the participants and researcher as continually evolving, (4) the active role of persons in shaping the world they live in through the processes of symbolic interaction.*

(Glaser 1992, p. 16)

Glaser (1992) and Strauss and Corbin (1990) were at variance on the criteria for developing rigour in grounded theory studies. Glaser (1978, 1992) proposed that fit, work, relevance, modifiability, parsimony, and scope are pertinent indicators through which theoretical rigour can be evaluated. Glaser and Strauss (1967) suggested that in order to establish rigour, then, qualitative academics need to detail more effectively “the actual strategies used for collecting, coding, analysing, and presenting data when generating theory” (Glaser and Strauss 1967, p. 244). In addition, Strauss and Corbin (1990, 1998) augmented the criteria of reproducibility and generalisability.

Conversely, Glaser (1992) disputed that these quantitative concepts were applicable to grounded theory studies. Strauss and Corbin (2008) advocated that the researcher is accountable for taking protective measures to substantiate areas of validity within their research. Meanwhile, Denzin and Lincoln (2005) proposed actions that can be employed to promote validity in a grounded theory study, which are: reflexivity, documentation, theoretical sampling, negative case analysis and transferability.

Birks and Mills (2015) suggest that the quality of a grounded theory study can be related to three distinct areas underpinned by (1) the researcher's expertise, knowledge and research skills; (2) methodological congruence with the research question; and (3) procedural precision in the use of methods; and that methodological congruence is authenticated when the researcher's philosophical position is congruent with both the methodological approach and the research question selected. Furthermore, Morse (2007) stated that data collection and analytical conceptualisation must be rigorous right through the research process to acquire quality in the grounded theory. The approach used to evaluate the rigour of this study's findings will be discussed later in this section 3.23.

### **3.10 The selection of the study site**

The study was conducted in a large Health and Social Care Trust in Northern Ireland. The Trust delivers health and social care to approximately 300,000 people across 4842 km<sup>2</sup>. The study site provides domiciliary care services to 4,500 individuals and has 1,800 residential and nursing home places.

Data collection and analysis were an ongoing process, most of the data were collected between May 2017 and May 2019. Semi-structured interviews were used to ascertain older peoples' experiences of moving from home to a care home over a one year period. As indicated earlier, purposive sampling was adopted in the initial phases of data collection, thereafter theoretical sampling was employed. Participants were recruited through older people locality managers, social workers within older people's community teams and by waiting lists held by care home managers within the Health and Social Care Trust. Meetings were held with social worker teams in two locations both urban and rural in an effort to enhance recruitment. The most effective method of recruitment was essentially through direct contact with care home managers. Although open to allegations of bias, this method of recruitment has been endorsed by Andoh-Arthur (2019) who stated that gatekeepers are essential as mediators when accessing study settings and participants within social research.

#### **Recruitment**

The sample was drawn from a list of nursing (n=21) and residential (n=4) homes located within the study site and registered with the Regulation and Quality Improvement Authority (RQIA).

In April 2017, face to face meetings were held with Locality Service Managers and Community Social Workers from the study site. The aim was to identify case managers who had clients approved to receive financial funding for a care home place. The next step was to meet with managers of the selected care homes to introduce the study (Appendix 6) and agree a protocol with the locality manager, social workers and care home managers for how to gain an introduction and access to potential participants (Appendix 7). This approach was adopted to enhance the response rate and support the early identification of potential participants. An information pack containing a cover letter (Appendix 8), and information sheet (Appendix 9) was delivered to all persons who met the following inclusion criteria:

Inclusion criteria: Persons who were:

- Waiting to move to a care home
- Aware of their planned admission to a care home.
- English speaking.
- Able to communicate and understand communication.
- Assessed to have minimal cognitive impairment as defined by the Mini Mental State Examination (MMSE  $\geq 24$ ) (24 or over)
- Able to understand the participant information sheet and had the capacity to provide informed consent.
- Willing to consent to being interviewed on 4 occasions during the study

A one week ‘cooling off period’ was originally given to participants after which time the researcher contacted them again to confirm their willingness to take part in the

study and to arrange consent prior to undertaking the first interview. However, accessing the sample in the seven-day period prior to the move proved to be problematic due to pressures on staff to transfer individuals to care homes as soon as possible to ease pressure on acute beds. Thus, once the funding was approved for the care home bed, individuals were often transferred within 2-3-days. In some cases, pre-admission assessments were undertaken by care home staff on the morning of the older person's admission to the care home. While this issue affirmed the importance of exploring this particular time-point in the transition to life in a care home, it became clear that the cooling off period of seven days was untenable for the research. With an amendment to ORECNI approval the selection criteria were therefore revised to enable recruitment of individuals within one-week pre and post the move to the care home and the 'cooling off period' was reduced to one day (Appendix 10). Thereafter, potential participants were contacted again to confirm their willingness to take part in the study and to make arrangements for obtaining informed consent.

Strauss and Corbin (1998, p. 201) described theoretical sampling as a means to "maximise opportunities to discover variations among concepts and to densify categories in terms of their properties and dimensions". As data collection proceeded, the basis of a theory began to emerge. However, as the preliminary findings were largely based on the experiences of older people in urban nursing homes, it was necessary to 'examine' this theory by theoretically sampling more people in residential and rural care homes. For example, some nursing home participants identified that care home staff were not keen to promote their mobility due to "fear of falling", so this was followed-up in subsequent interviews with older people in residential care settings. This is wholly consistent with grounded theory methodology

where concepts rather than individuals are sampled. Therefore, potential participants moving to these types of care homes were invited to take part in the study.

### **3.11 Ethical issues**

Ethical approval for the study was obtained through the Institute of Nursing and Health Research, Ethics Filter Committee, Ulster University (Appendix 11). Ethical approval was also obtained from Office for Research Ethics Committees Northern Ireland (ORECNI) (Appendix 12) and from the Clinical and Social Care Governance Committee of the Trust site (Appendix 13). Sponsorship in relation to governance and indemnity was obtained from the Research Office at Ulster University. The International Council of Nurses (ICN) Code of Ethics (2006) which relates to the protection of vulnerable adults, underpinned all aspects of ethical considerations for this study. A Distress Protocol was developed (Appendix 14 ) and a system of referral and escalation was put into place taking due cognisance of the Protection of Vulnerable Adults Guidelines (Department of Health Social Services and Public Safety, DHSSPS, 2006), for implementation should any participant become distressed during interview. A protocol for disclosure of unprofessional practice (Appendix 15) was also developed. Personal knowledge and experience as a mental health nurse was beneficial in the identification of early signs of distress when undertaking the interviews. In addition, participants were asked if there was somebody, they would like to be present during the interview, or who could be a contact person should they become upset. In the event, no participant became very distressed. Some individuals gave emotional responses during the interviews, especially those who highlighted the urgency of their move to the care home. In adherence to the Distress Protocol (Appendix 14), the interviewer and participant talked about this, and in each case, the

participant requested that the interview proceed, and indeed explained that talking about their experiences was supportive. The care home manager was informed after the interview if a participant became upset. If these instances occurred, the participant was not left alone until he/she was content.

Informed written consent was provided by each participant prior to the interviews and this included permission to use a digital recorder (Appendix 16). Assurances of confidentiality and anonymity were provided and was supported by the allocation of pseudonyms in the presentation of the study findings. The main ethical issues related to the protection of vulnerable adults, participant information, consent, autonomy, and confidentiality. The inclusion of case/home managers as a link between myself and potential participants afforded additional protection to study participants. The participant information sheet (Appendix 9) and consent form (Appendix 16) highlight the confidential nature of the information obtained in the course of the study. Throughout the data collection period, participants were reminded of the confidential nature of the interviews and of their right to withdraw from the study at any time.

### **3.12 Data collection**

Some researchers have identified that pilot studies are useful in improving researcher confidence, and skills in conducting qualitative research, which in turn improves the overall credibility of the study (Janghorban *et al.* 2014; Ismail *et al.* 2018). Conversely, it has also been suggested that pilot studies are not essential as the entire process of data collection and analysis incorporates refining strategies, methods of thinking and recognising alternative paths (Harding 2013; Ismail *et al.* 2018). A pilot

study was not undertaken for the following reasons. Firstly, previous experience of conducting interviews with older people in nursing homes had highlighted pitfalls that might occur: For example, ensuring adequate time and resources, an open environment, and good recording equipment. Secondly, because participants were experiencing a significant life changing transition, it seemed unethical to use them to test interview questions without following their entire transition throughout the first year of their life in a care home. Thirdly, theoretical sampling emphasises the need to sample on the basis of themes or concepts as opposed to individuals themselves. Therefore, each interview is different from the previous one. Undertaking a pilot study did not seem a rational methodological approach to take for the sake of an interview schedule.

Data collection and analysis were ongoing processes, with most of the data being collected between May 2017 and May 2019. At the same time, supplementary data were collected over the entire study period. Although not initially apparent, as the study progressed, the significance of Glaser's (1998) view that 'all is data' became apparent in the context of emergent categories. Potential sources of data included personal interactions with older people, and social and media outlets including a story in a local newspaper from one of the participants in the study entitled '*A great place to grow old*'. The context of these experiences provided opportunities for reflection, constant comparison and theoretical memos and will be discussed in more detail in the findings chapter.



### **3.13 Semi-structured interviews**

Gray (2018, p. 379) defines interviewing as ‘a basic form of human activity in which language is used between two human beings in the pursuit of cooperative inquiry’. Interviews have been considered the most suitable method of data collection in grounded theory research as they facilitate moving backward and forward between data collection and analysis until the emerging theory is saturated (theoretical sampling) (Creswell 2009; Straus and Corbin 2008; Bryman 2016). A semi-structured interview was chosen as it provided both focus and flexibility, consistent with Strauss and Corbin’s (1998) grounded theory methodology. Active listening and flexibility were adopted to facilitate the participant’s conversation (Kvale 2006; Kvale and Brinkmann 2009; Silverman 2013; Mears 2017). Consistent with a grounded theory approach, a broad interview topic guide was used (Appendix 5). Questions were adapted in later interviews to explore emerging themes and to capture a deeper understanding of the issues arising (Charmaz 2006; Glaser and Strauss 1967).

As per the recruitment protocol, once the case managers and care home managers approached prospective participants, a letter of invitation (Appendix 8) was provided to those who expressed an interest in the study. This contained a brief outline of the study and informed those who expressed an interest that their participation would involve four one-to-one interviews, over the course of the first year of their life in a care home. Following on from initial contact by letter, participants were telephoned to confirm their interest in the study, and to arrange a suitable time and venue to meet to provide further details.

## Cognitive Assessment

Universally, cognitive assessment tools are used to screen patients for cognitive impairment, differential diagnosis, and ascertaining disease severity and progression (Tavares-Júnior et al. 2019). The Mini-Mental State Examination (MMSE) (Folstein et al. 1975), is an instrument used extensively to assess cognitive status (Wood et al. 2006). Several researchers have explored the relationship between MMSE scores and consent capacity, and the results have been mixed (Clark et al. 1999; Kim et al. 2002). It has been reported that the MMSE is unduly influenced by age and educational level (Brooke and Bullock, 1999; Tiwari et al. 2009) and any sensory deprivation may bias the results of the examination (Foreman et al. 1996). Furthermore White et al. (2002) found that the MMSE had an unacceptably high false-positive rate in identifying cases of dementia in primary care. The MMSE was utilised in this study to determine participant's minimal or no level of cognitive impairment as defined by a score of  $\geq 24$ , which was a criterion for their inclusion in this study. The rationale for this was that data collection was carried out over a 12 month period and relied upon participants ability to recall and reflect upon their experiences over this extended time frame. At the first meeting and with the participant's consent, an MMSE baseline assessment was undertaken to confirm their cognitive ability. The MMSE was administered at the commencement of each engagement as part of the structured interview when discussing participants demographic characteristics and general health. Consenting participants were subsequently reassessed using the MMSE prior to interviews 2, 3, and 4 to assess any changes in their cognitive ability over time. On each occasion participants verbally completed the MMSE and the researcher entered answers to interview questions on individual score sheets. Paper and pencil responses were used for the two items requiring written responses.

## Conducting the Interviews

Participants were interviewed face to face, in their homes, care homes or in the hospital prior to the move to the care home. Having met each participant once before the first interview, it was important to introduce myself again and express thanks for their help with the study. At the start of the first interview, background information about the study, personal interest in the topic and the confidential nature of the interview was reviewed. It was important to develop a rapport with the person and this was achieved by spending time talking about everyday issues such as the weather, local news, or items of interest. When the participant had relaxed, brief biographical details were noted down.

It was important to be mindful that some participants might find a digital recorder disconcerting. Indeed, it has been identified that the use of technology can be distracting and unsettling for individuals who may worry about their words ‘going on record’ (Bryman 2016; Mears 2017). To allay possible anxiety, a very small recording device was used out of sight with the participants’ consent.

## Interviews 1 and 2

During the first interview, participants were asked to discuss their present day experiences, views on their current situation and expectations of living in the care home. Participants were interviewed again within 4 -6 weeks of arrival in the care home to determine their reactions to the setting. This interview focused on perceived differences between expectations and experiences of the care home and between this new environment and their own home. Furthermore, expectations for the future and

perceived physical, social, and psychological well-being of participants were explored.

#### Interviews 3 and 4

Approximately 4-5 months after moving to care home, participants were interviewed again to discuss their feelings about permanent residency in the care home. Questions were adapted from previous interviews to explore emerging themes. A final interview at 9-12 months was undertaken to explore participants' current experiences of the transition to life in a care home with a focus on the factors that facilitated or hindered this transition. At the end of every interview and beginning of the next, issues arising were identified which helped with further clarification where necessary. The interviews themselves by and large went exceptionally well, in part due to the rapport developed over the year. None of the planned interviews were cancelled, helped in part by confirming and ensuring that participants were still willing and able to be involved. While a general interview guide had been prepared (Appendix 5), this was revised as data collection, analysis and interpretation progressed. The aim was to pursue emergent themes in keeping with grounded theory methodology (Glaser and Strauss 1967; Strauss and Corbin 1998). Throughout the data collection period, issues raised by participants in earlier interviews which were considered to be important were introduced into subsequent interviews by asking participants "Other people have said that.....what do you think?". However, it was important to be mindful of the phenomenon called 'the interviewer effect' (Bryman 2016), that is, not to distort the interview process by trying to obtain data in the direction of my own thoughts. Birks and Mills (2015) state that undertaking grounded theory research necessitates a balance between keeping an open mind and the aptitude to identify aspects of

theoretical significance during data generation and/or collection and data analysis. The final phase of the interview was essentially one of summary and closure.

### **3.14 Theoretical saturation**

In their first publication on grounded theory, Glaser and Strauss (1967, p. 61) defined saturation as:

*The criterion for judging when to stop sampling the different groups pertinent to a category is the category's theoretical saturation. Saturation means that no additional data are being found whereby the sociologist can develop properties of the category. As he sees similar instances over and over again, the researcher becomes empirically confident that a category is saturated. He goes out of his way to look for groups that stretch diversity of data as far as possible, just to make certain that saturation is based on the widest possible range of data on the category.*

Urquhart (2013, p. 194) defines saturation as ‘the point in coding when you find that no new codes occur in the data. There are mounting instances of the same codes, but no new ones. Furthermore, Morse (2015, p. 587) states that data saturation is ‘the most frequently touted guarantee of qualitative rigor offered by authors. Therefore, in order to ensure that meaningful and valid results are developed, it is essential that the researcher ensures that saturation has occurred (Glaser and Strauss 1967; Corbin and Strauss 1998). As indicated earlier in this chapter, theoretical sampling continued until the emerging concepts and categories reached saturation. In practical terms, theoretical saturation became apparent after the event. When nearing data saturation, it was vital to undertake further planned interviews to confirm this view. Several similar categories had been developed, consequently, during the course of reflexivity and memo writing it was decided that many categories were the same and required

more conceptual thinking. Having concluded that little in the way of new data could have been added to any category by further interviews, theoretical saturation was deemed to have been reached.

### **3.15 Data management**

As stated previously, all interviews over the four timepoint periods were recorded with the consent of participants. The Martha McMenamin Scholarship monetary award that had been obtained paid for the professional transcribing of the tapes. To check for accuracy, all of the tapes were listened to in order to become familiar with the voices of the participants and to make amendments if some pieces of information were omitted. This also provided an opportunity to stop the flow of conversation and to focus on details, such as hesitations, restarts, and cut-offs in participants' speech (Silverman 2013).

During the study, a research journal was used to write theoretical memos and to keep field notes. Field notes are useful in gathering observational data to record the participants' verbal and nonverbal behaviour and the context in which these behaviours take place, including the researcher's own thoughts, feelings, impressions, and insights (Miles and Huberman 2009; Flick 2014). Additionally, field notes are often used in combination with theoretical memos and researcher journals to record the researcher's conceptual reasoning and methodological decisions (Miles and Huberman 2009; Flick 2014). On some occasions, at the end of the interview when the digital recorder was switched off, some participants continued to reflect on their experiences and new data often emerged. On these occasions, permission to take notes to include these in the interview was requested, which all of the participants agreed

to. Thereafter their comments were documented and transferred, at a later time, to the research journal.

Data analysis was informed by open, axial, and selective coding principles as espoused by Corbin and Strauss (2008). Simultaneous data collection and constant comparative analysis were undertaken and repeated until theoretical saturation was achieved when no new categories were identified, and until new instances of variation for existing categories ceased to emerge. The final stage of selective coding was the process of integrating and refining categories, a core category was identified that related to the other categories, validating those similarities and relationships (Strauss and Corbin (1998).

#### QSR NVivo

NVivo 12 qualitative data analysis programme software (QSR International 2012) facilitated the organisation, management and retrieval of transcribed interviews and field notes and provided tools for coding, categorising, and linking qualitative data (Bazeley 2013). The efficacy of computer-assisted qualitative data analysis (CAQDAS) and NVivo 12 in organising large amounts of unstructured interview data into workable codes for more efficient analysis has been identified (NVivo 2018). Furthermore, NVivo can facilitate many aspects of the iterative process connected with grounded theory and can help support a transparent account of this, which should ultimately enhance study validity (Bringer *et al.* 2004). Prior to the commencement of data collection, NVivo training was undertaken. This proved to be beneficial as NVivo 12 assisted with the process of immediate coding from the interview transcripts, the emerging themes could then be grouped as appropriate. Appreciably,

the ability to store and code considerable amounts of text meant that the context of conversations were not lost in the analysis. NVivo also facilitated with axial coding, i.e. making associations between the codes so as to merge similar codes into broader categories. In addition, traditional materials of coding, for example, coloured pens and paper helped to provide a visual analysis and mapping of codes to see interaction and reasoning. This practice increased the opportunities for interpretative insight directing a more rigorous analysis process.

### 3.16 Theoretical memos

A core stage of generating theory in grounded theory methodology is the writing of theoretical memos. Glaser (1998) considers that:

*Memos are the theorizing write-up of ideas about substantive codes and their theoretically coded relationships as they emerge during coding, collecting and analysing data, and during memoing.*  
(p.177)

Strauss (1987) provides further elaboration when he describes theoretical memos as:

*writing in which the researcher puts down theoretical questions, hypothesis, summary of codes, etc—a method of keeping track of coding results and stimulating further coding, and also a major means for integrating the theory.*  
(p. 22)

Strauss and Corbin (1990) state that researchers have to develop their own style of recording memos, which may include the use of software, colour coded cards, and recordings in folders or notebooks. They emphasise the importance of having a



systematic approach which includes dating each memo and its source so that they can be recovered easily. In this study, the process of documenting memos commenced with the first coding of the data and continued throughout the research process (Glaser and Strauss 1967; Strauss and Corbin 1992). Writing regular reflections helped to document comments and memos and to record thoughts about the codes and their relationship to each other in a journal. Many self-reflective memos led to questions which helped analyse and interrogate interview transcripts further. Memos played three roles within analysis which were: 1) Giving context to sources of information, interviews, and observational data, 2) Making proposition statements and 3) Defining nodes and connecting categories with each other and with their subcategories.

In practice, theoretical memos were written at various stages of the research process. At the beginning they appeared somewhat simple as outlined below (Figure 3.1) but became more advanced during the phases of axial and selective coding and finding the core category (Figure 3.2). Also, in keeping with the recommendations of Strauss and Corbin (1998), all the memos were dated and linked to the source from which they were derived.

**Figure 3.1:** *Theoretical Memo- Meeting with Care Home managers*

**24.04.17. Meeting with Care Home Managers**

Care home managers have reported that on frequent occasions they were asked to undertake a patient care assessment in the morning and due to the pressures of freeing up hospital beds were asked to accommodate having the older person move to the care home that very evening. This has left managers feeling pressurised and frustrated that individuals were not getting time to prepare for the relocation to a care home.

25.04.17 Follow up phone call with locality service manager who confirmed urgency of care home admission due to finance for a place being granted on a weekly basis. I think the urgency of these admissions have reaffirmed the criticality of the pre- move point of transition to the care home and this will be an important part of the development of the theory within the grounded theory study.

**Figure 3.2: Theoretical Memo- Developing the Core Category**

**23.08.18 Paradigm model and core category- ‘You’re at their Mercy’.**

The core category linked the contextual and intervening conditions of experience of hospital care, having to make abrupt departures from home, and participants own thoughts about the move, with the action/interactions of health and social care practitioners who were organising and arranging the move. There was a perceived lack of decision making and choice of the care home and the move itself was being instigated by others. The consequential outcomes are that individuals are trying to maintain their own self-identity and connections to family and home after the move. Therefore, these constructs are linked to the core category and the main theme for this first transition timepoint within this study. It is clear to me now that the older people in this study appear to see themselves as being powerless as a result of others, for example, family members, social workers, community care managers and care home staff, all of whom are perceived to be making decisions on their behalf. Closely linked to their feelings of being dependent on others is the strong sense of disempowerment that permeated most individuals’ experiences. In the absence of any opportunity or encouragement to have their voice and choice heard, they appear to display a resigned acceptance to their fate. It is a solid core category as it conveys theoretically what the research at this point of the transition process is all about, individuals are dependant and ‘at the mercy’ of others. Upon reflection I think that perceived level of dependence has been evident for a long time, but I wanted to go cautiously. I sought further understanding from field notes and previous theoretical memos. This first piece of the analytical storyline is now in place for to be applied to the theory generation within grounded theory. It is significant that even though international literature would indicate that moving to a care home is a traumatic and life-changing experience, the importance of the move would not appear to be recognised or supported by formal services.

### **3.17 Selecting the correct analytical approach for the study**

Considering which model of data analysis to choose took time and reflection. After much deliberation the data for this study were analysed using the framework put forward by Strauss and Corbin (1990) which was later refined in the second edition of their work entitled ‘Basics of Qualitative Research, Techniques and Procedures for Developing Grounded Theory’ (Strauss and Corbin 1998). Strauss and Corbin (1990, 1998) adopted a detailed, systematic, and more prescriptive approach, which, according to Glaser (1992), forced the development of a theory. Glaser (1992) believed that Strauss and Corbin (1990) had omitted 90% of their original ideas in

text. Glaser and Strauss (1967) and Glaser's (1978) publications were also 'excluded' from the revision. This triggered accusation of deduction and "... *forced, preconceived, full conceptual description*" (Glaser, 1992; p3). Strauss and Corbin asserted that their approach had evolved over time (Strauss and Corbin 1994). Methodologies do evolve over time and are revised to fit a transforming historical or philosophical milieu (Ralph *et al.* 2015). The grounded theory model developed by Strauss and Corbin (1998) seemed most appropriate, because of the proposed framework in terms of the data generation and coding procedures that are used to guide the analytic process of generating a theory. Furthermore, Strauss and Corbin stress that the components of the model are designed to guide rather than restrict the researcher and if used appropriately the model will serve to facilitate the generation of a more creative way of undertaking grounded theory.

### **3.18 Coding**

Strauss and Corbin (1998) contend that grounded theory involves interplay between induction and deduction, and this ensures the rigour of the approach. Consequently, grounded theory is a largely inductive approach, but the process of coding and analysing involves both induction and deduction. In this study, data analysis was informed by open, axial, and selective coding principles as espoused by Corbin and Strauss (2008). Simultaneous data collection and constant comparative analysis were undertaken and repeated until theoretical saturation was achieved when no new categories were identified, and until no new instances of variation for existing categories emerged. The final stage of selective coding was the process of integrating and refining categories. A core category was identified that related to the other categories, validating those similarities and relationships (Strauss and Corbin, 1998). The process of open, axial, and selective coding is outlined below.

### i. Open Coding

Open coding (Strauss and Corbin, 1998) focuses on the conceptualisation and categorisation of phenomena through an intensive analysis of the data. The ultimate aim of open coding is to develop a multitude of codes with which to describe the data (Strauss and Corbin 1990). Arranging concepts into categories is an important part of grounded theory as it enables the researcher to reduce the number of units with which they are working. In addition, “.... *categories have analytical power because they have the potential to explain or predict*” (Strauss and Corbin 1998, p.113) and this is a key aspect of a theory. An example of coding exemplars is provided in Appendix 17 to illustrate the relationship between codes, categories, and subcategories in the different stages of the paradigm model. Open coding can be undertaken formally and systematically or quite informally. It involves reading through the data several times to create tentative labels for pieces of data that summarise what is happening based on the meaning that emerges from the data. The initial transcripts were examined on a line-by-line basis when repeated ideas, concepts or elements became apparent, and they were tagged with codes extracted from the data. This involved the use of ‘in vivo’ codes using participants own words. Codes that had similar meaning were linked together and renamed as categories to provide more abstract meaning. In addition, each property or characteristic of the category were located along a continuum (Strauss and Corbin 1998) for example perceptions of health as in “deterioration in health” and “health uncertainties”. In addition, as codes were developed, memo writing aided the process of constant comparative analysis. Codes (known as nodes in NVivo language) were then sorted into categories and sub-categories. The NVivo software package facilitated this process well, as it enabled concepts to be assigned to

one or more categories until the theory began to emerge. Towards the end of the process, long sentences or paragraphs were coded to different themes/categories. As saturation was pending, that is, when no new categories were being identified, it was more useful to look at a transcript in its entirety.

## ii. Axial Coding

Strauss and Corbin's (1998, p. 123) define axial coding as "the process of relating categories to their subcategories, termed 'axial' because coding occurs around the axis of a category, linking categories at the level of properties and dimensions". Axial coding is referred by Corbin and Strauss (2008, p. 195,) as "crosscutting or relating concepts to each other". The ultimate aim is to develop one of several main categories and to place "the fractured data back together in new ways after open coding, by making connections between a category and its subcategories" (Strauss and Corbin 1990, p. 96). Researchers are required to consider three aspects of the phenomenon if these connections are to be attainable. These are the situations in which phenomenon occurs; how people react in such situations; and the consequences of the action taken or inaction (Strauss and Corbin, 1998). Addressing these aspects can help the researcher to: "... conceptualise a phenomenon, that is, to locate it within a conditional structure and identify the 'how' or the means through which a category is manifested" (Strauss and Corbin 1998, p. 127).

Axial coding facilitates the researcher to integrate, inter-relate and unify categories. As analysis progressed, coding moved towards focusing on those codes which related to emergent main categories. According to Strauss and Corbin (1990), a key category must appear frequently within the data, and correlate easily to other categories and

have explanatory power. Key categories are crucial to grounded theory as they guide theoretical sampling and data collection.

### iii. Selective Coding

Strauss and Corbin (1998) indicate that selective coding requires the researcher to recognise when to stop coding in order to selectively code for a core category. Strauss (1987, p. 33) explains that “selective coding pertains to coding systematically and concertedly for the core category”. Strauss and Corbin (1998) emphasise that at this level of coding, it is crucial that categories are finally integrated to form a larger theoretical scheme for the research findings to take the form of theory. In this study the final stage of coding and process of identifying and choosing the central concept occurred by systematically connecting it to other categories and validating those similarities and relationships. The relationship between categories constitutes substantive theory (Corbin and Strauss 2008).

### **3.19 Discovering the central category**

Strauss and Corbin, (1998) state that the core category is central to and links the data, and accounts for the variations in the data. It ought to be an abstraction and analysed in a few condensed words that seem to afford and give an explanation about what the research is all about. Also, Strauss and Corbin, (1998, p.146) suggest the central category should have analytic power which gives it the “ability to pull the other categories together to form an explanatory whole”. Corbin and Strauss (2008, p. 105) provide the following advice with respect to choosing a central category:

1. It must be abstract; that is, all other major categories can be related to it and placed under it.
2. It must appear frequently in the data. This means that within all, or almost all, cases there are indicators pointing to that concept.
3. It must be logical and consistent with the data. There should be no forcing of data.
4. It should be sufficiently abstract so that it can be used for research in other substantive areas, leading to the development of a more general theory.
5. It should grow in depth and explanatory power as each of the other categories are related to it through statements of relationship.

### **3.20 Filling in poorly developed categories**

In grounded theory, categories may be identified as needing further development if not all of their relevant properties are well-defined or inadequate evidence has been gathered regarding how well their components are empirically grounded. Accepting such disparities would result in a theory with less conceptual density and/or less specificity than is possible and desirable (Strauss and Corbin 1990). The solution is to go back to the data or collect more data specifically targeted at filling these gaps.

In this study the filling in of poorly progressed categories required the use of field memos, reviewing data over again in case something was overlooked and collecting more data. As data saturation was achieved a few such concepts that had been followed initially did not warrant further theoretical sampling. One such concept was the categorisation of participants selling their house contents, and another example

was ‘things going missing’ in the care home. As it turned out these occurrences happened so infrequently and contributed little to the overall theory.

### **3.21 The Paradigm Model**

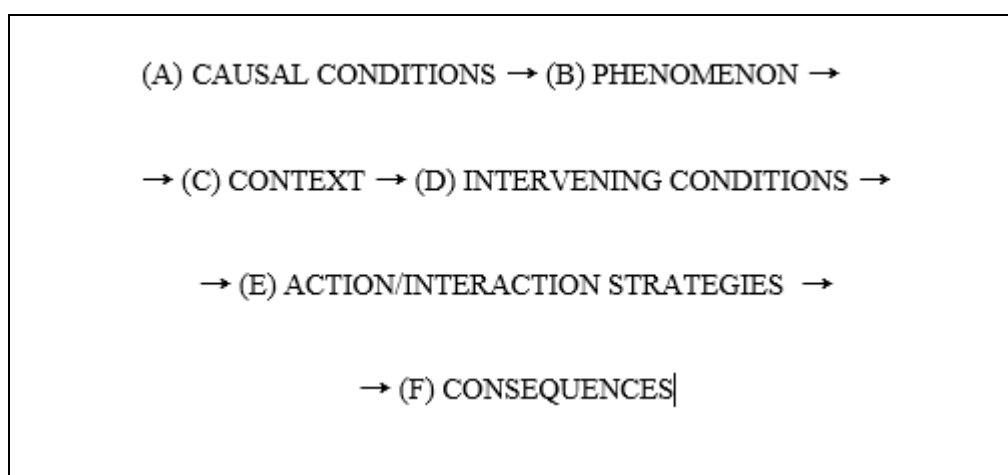
Strauss and Corbin (1998) and Corbin and Strauss (2008) indicate that one of the most significant aspects of grounded theory approaches lies within their description of the paradigm model (Figure 3.3). This model was devised to support the researcher with numerous and complex concepts and interrelated relationships. Corbin and Strauss (2008, p. 89) emphasised:

*The paradigm is a perspective, a set of questions that can be applied to data to help the analyst draw out contextual factors and identify relationships between context and process.*

Corbin and Strauss (2008, p. 89) also advocated that there are three fundamental components to the paradigm model as follows: 1. There are conditions. These allow a conceptual way of grouping answers to the questions about why, where, how, and what happens. 2. There are inter/actions and emotions. There are the responses made by individuals or groups to situations, problems, happenings, and events. 3. There are consequences. These are the outcomes of inter/actions or of emotional responses to events. Consequences answer the questions about what happened as a result of those inter/actions or emotional responses?



**Figure 3.3:** *The Paradigm Model (Strauss and Corbin, 1990;1998)*



Strauss and Corbin state that the basic components of the paradigm model are as follows. Conditions are a conceptual way of arranging answers to the questions where, how come and when:

*.... Labels placed on conditions such as causal, intervening, and contextual are ways of trying to sort out some of the complex relationships among conditions and their subsequent relation to actions/interactions.*

(Strauss and Corbin 1998, p. 131)

### Causal Conditions

Causal conditions normally refer to events that influence phenomena. Intervening conditions change the effect of causal conditions on phenomena and these frequently arise because of untoward events which subsequently lead to some form of action/interaction. Contextual conditions are conditions that interconnect dimensionally at a time and place to create the set of circumstances or issues to which participants react through actions/interactions. Strauss and Corbin (1998) emphasised the significance that it is not so much of one identifying which conditions are causal,

intervening or contextual, but more accurately the relationship that exists amongst all of these things, and the associated actions/interactions and consequences.

### Actions/Interactions

Actions/interactions are responses made by individuals or groups to problems or events that arise from conditions and are denoted by the questions by whom and how. Consequences are outcomes of actions/interactions and are represented by questions concerning what happens because of those actions/interactions. Every time there is an action or interaction there are a range of consequences, both expected and unexpected “.... *Delineating these consequences and explaining how they alter the situation and affect the phenomenon in question provides for more complete explanations*” (Strauss and Corbin 1998, p. 134). Finally, ‘phenomenon’ is a term that responds to the questions “what is going on here?”. In exploring phenomena, grounded theorists are looking for patterns of events or actions/interactions that signify how people act or say in response to their situation.

### Arguments around analytical tools

Both Glaser (1992) and Charmaz (2006) argue that the level of researcher involvement and use of analytical tools can force data into predetermined ideas instead of allowing the grounded theory to emerge. Conversely, some researchers assert that the rigorous analytic tools, for example the coding paradigm, can enable the construction of appropriate analytical theories (Mills *et al.* 2006). Nevertheless, others contend that analytical tools are inflexible, concentrating on systematic procedures that impede the researchers’ sensitivity to the data, pushing a power

distinction amongst the researcher and participants (Bryant and Charmaz 2007; Evans 2013).

Although the concepts embedded in the “paradigm model” were useful in deliberating how to connect sub-categories with categories, the structure of the paradigm model could at times be constricting. Not all sub-categories of a category could be easily labelled as causal conditions, context, intervening conditions, action-interaction strategies, or consequences.

### **3.22 Ensuring rigour**

Lincoln and Guba (2000) maintain that qualitative research cannot be assessed on the positivist idea of validity, rather it should be judged on trustworthiness. Polit and Beck (2017) propose that the rigour or trustworthiness of a research study refers to the level of confidence in the data, interpretation, and methods employed to ensure the quality of a study. Strauss and Corbin (1998) and Corbin and Strauss (2008) did not specify how to validate quality. However, a frequently used framework put forward by Beck (1993), identified credibility, auditability, and fittingness as the main criteria of rigour for qualitative research. These principles are now evaluated.

#### **i. Credibility**

Beck (1993, p. 264) suggested credibility is a term that relates to ‘how vivid and faithful the description of the phenomenon is’. Conversely, Glaser and Strauss (1967) contended that the reader should ‘almost literally see and hear the people’ in the study. Moreover, Strauss and Corbin (1998) state that the theory should be recognisable to participants, so a vivid explanation is essential. This statement is supported by Lincoln

and Guba (2000) who proposed that a study is trustworthy when it offers such a vivid and faithful account that people who have experienced the phenomenon would immediately identify the discoveries as their own. A means to enhance the credibility of the study is embedded within the grounded theory method by means of concurrent data collection, data analysis and ‘checking’ of emerging categories against the data (Strauss and Corbin 1998).

Within this study, various strategies were utilised to ensure rigour. The study was conducted with an awareness and application of the underlying principles of the authenticity criteria developed by Nolan *et al.* (2003) and further developed in care homes research by Wilson and Clissett (2011). Equal access promoting accessible and comprehensive information to all participants about the nature of their involvement with the study was given. In the grounded theory approach, validity depends on theoretical sensitivity, which refers to the ability to give meaning to data and the capacity to understand; the sources of theoretical sensitivity (Strauss and Corbin 1990). The initial interviews were recorded and checked to ensure the rigour of the data collection procedures. No formal member checking was performed within this study; however, the constant comparison of emerging data facilitated the verification of findings and minimised the likelihood of personal bias. As data collection proceeded and the basis of a theory began to emerge, it became necessary to theoretically sample older people in residential and rural care homes as interim findings would indicate something different about the experiences of older people in care homes within an urban environment. Strauss and Corbin (1998, p. 201) have described theoretical sampling as a means to “maximise opportunities to discover variations among concepts and to densify categories in terms of their properties and

dimensions". Therefore, potential participants moving to these types of care homes were invited to take part in the study. Similarly, if individuals mentioned anything that was considered to be of interest, this was followed-up in subsequent interviews. The process of theoretical sampling continued until the emerging concepts and categories reached saturation. Repeatedly emerging concepts and categories were thought to have high levels of truth and value, while concepts and categories that were not verified by subsequent data were considered to be lacking in truth and consistency.

## ii. Auditability

Guba and Lincoln (1981, 1989) state that the credibility of qualitative findings can be determined using an audit trail of the research process. This includes providing a clear trail of the decisive phases of the research. Consequently, the purpose of an audit trail is to enable the reader to form opinions about methodology and analysis by displaying these in an 'auditable form'. In addition, Strauss and Corbin (1998) have specified that researchers should acknowledge their personal assumptions, values and biases and discuss how these may have affected theory development. They recommended using journals (Strauss and Corbin 1998; Corbin and Strauss 2008) to recall any deliberation, thoughts and feelings during data collection and analysis phases as well as analytical techniques for example, 'waving the red flag' aiming to challenge the researcher's presumptions.

According to Koch (1994), an audit trail will present the reader with confirmation of the choices and decisions the researcher has made in relation to theoretical and methodological issues throughout the study. This necessitates a clear rationale for such decisions made. Sandelowski (1986) supports this assertion stating that study

findings are auditable when another researcher can distinctly follow the decision trail. The data collection and data analysis employing theoretical sampling and constant comparative analysis was solely the responsibility of the principal researcher. However, during the open and axial coding stages, a significant advantage to data analysis was provided by one supervisor who independently viewed the original uncoded manuscripts and confirmed themes thus ensuring that interpretations represented the experiences of the individuals. After the selective coding process, all members of the PhD supervision team enhanced trustworthiness of the data by meeting to discuss the emerging themes and these themes were reviewed and revised as needed. All of these senior researchers provided supervision, direction and appropriate challenges to all assertions and data analysis procedures. Therefore, interpretations of the data were seen as credible, dependable, and confirmable (Lincoln and Guba 1985). Previously in this chapter, the rationale for choosing this methodology was outlined. Chapter Four presents the analytical story line. The diagrammatic representations of the emerging models at the different timepoints provide further substantiation and clarity of the relationship between the core categories and the subcategories. The coding exemplars in Appendix 17 clarify this process and explain the relationship between the major categories and the raw data. These exemplars contain narrative examples in addition to those used in the findings chapter. The audit trail is considered to be the most substantial evidence of this study's credibility.

### iii. Fittingness

Koch (1994) states that fittingness also refers to transferability and is reliant on the degree of comparison between two contexts. Sandelowski (1986, p. 32) explained that

“a study meets the criterion of fittingness when its findings can [fit] into contexts outside the study situation and when its audience views its findings as meaningful and applicable in terms of their own experiences”. Beck (1993, p. 264,) describes fittingness as a reflection of how applicable the ‘working hypotheses or propositions generated from the research fit into a context other than the one from which they were generated’. In this study, the parameters of the research in terms of the sample, setting and level of theory generated are described. The demographic characteristics of the sample included age, gender, source of entry to care home, and type of care home.

Strauss and Corbin (1990) suggested that the theory must be ‘faithful to the everyday reality of the substantive area and (if) carefully induced from diverse data, then (it will) fit that substantive area’. To develop fittingness in grounded theory research, it is important to ascertain the level of theory generated. The theory generated in this study is a substantive theory, since the theory evolved ‘from the study of a phenomenon which was the exploration of older peoples’ transitions to a care home environment (Strauss and Corbin 1990, p. 174).

By determining and emphasising similarities between the findings of this study and previous studies or theoretical constructs in the literature, it is feasible to show the transferability of the phenomena explored. By showing the likelihood that the research findings will have significance and meaning to health care professionals, academics, theorists, or researchers will require an explanation of how the literature correlated to each of the categories within the generation of the theory. Certain aspects of the literature are discussed within the findings sections and other important elements are further deliberated on within the discussion chapter. Significantly however, as

Chiovitti and Piran (2003, p. 433) suggested: “The final judgement of the transferability of the findings rests with the reader”. Although Corbin and Strauss (2008) have asserted that by adhering to the model, rigour and vigour will be established, they also advised that it had some limitations. Despite these appraisals a critical interpretation of the three core areas of credibility, auditability and fittingness have been detailed.

### **3.23 Chapter Summary**

This chapter has presented a consideration of methodological approaches within the overall study design. Significantly, the grounded theory methodology outlined by Strauss and Corbin (1990, 1998), informed by a post-positivist theoretical perspective was preferred. The reason for this decision relates to grounded theory affording opportunity for inductive enquiry, by means of generating new theory and new insights, and requires the researcher to identify the research problem from the research participants’ perspectives. Issues relating to the core components of grounded theory methods, including data collection and analysis, simultaneous coding and analysis, constant comparative analysis have been discussed. This chapter has also highlighted key ethical issues, as well as the measures taken to ensure rigour and credibility of the study findings. The next chapter will present findings from the identified timepoint periods of the transition to a care home.



## CHAPTER FOUR:

### FINDINGS

#### 4.1 Introduction

The previous chapter explored grounded theory methodology and provided a rationale for why the specific approach of Strauss and Corbin (1990, 1998) was chosen to explore the experiences and perceptions of older people during the transition from living at home to living in a care home. The aim of this chapter is to focus on the research findings. The chapter is divided into four sections, the first section outlines the participant profiles, details of care homes and participant characteristics. The interview findings are presented in three stages: the first interview which either occurred pre-move (7 days) or post-move within 3 days of the move to the care home; interview two which occurred between four and six weeks post move; interview three (at 4-5 months) and interview four (at 9-12 months). Data analysis of interviews three and four are presented together as there was not a significant difference in the concepts and categories emerging from the data to warrant a separate section. The three published papers relevant to the findings of the study are:

**Paper One:** O'Neill M, Ryan A, Tracey A and Laird EA (2020) "You're at their Mercy": Older peoples' experiences of moving from home to a care home: A grounded theory study. *International Journal of Older People Nursing*, e12305. <https://doi.org/10.1111/opn.12305>

**Paper Two:** O'Neill, M., Ryan, A., Tracey, A., and Laird, L. (2020). 'Waiting and Wanting': Older peoples' initial experiences of adapting to life in a care home: A grounded theory study. *Ageing and Society*, 1-25.

<https://doi:10.1017/S0144686X20000872>

**Paper Three:** O'Neill M, Ryan A, Tracey A and Laird EA (2020) 'The Primacy of 'Home': An exploration of how older adults' transition to life in a care home towards the end of the first year. *Health and Social Care in the Community*. (Appendix 1)

The final section of the chapter will focus on the overall paradigm model and the identification of a core category that emerged from the analysis of the data collected over the course of the first year of the move to a care home. The emergence of a substantive theory '*The centrality of connection in supporting older people on their journey from life at home to life in a care home*' is also discussed. The final part of the chapter provides a summary of the findings, in addition to a summary of the overall chapter content.

## 4.2 Profile of participants

The participants in this study (n=23) comprised of both females (n=14) and males (n=9) with an average age of 82.4 years. All participants identified as being of white Caucasian. Thirteen participants were admitted directly from hospital: female (n=6) and male (n=7). In comparison, more females (n=8) than males (n=2) were admitted to the care home directly from their own home. The majority of the individuals (n=14) were living alone at the time of admission to the hospital/care home, while the remaining participants (n=9) lived with a spouse/ family member. Of the nine

participants that were living with a spouse or family member, five reported that community care services could no longer meet their needs. The main reasons cited for the relocation to a care home were a deterioration in their physical health (n=17), recent bereavement (n=3) and ‘no-one to take care of me’/changing family circumstances (n=3). Only four participants independently made the decision to move to a care home, and of these four, only two were able to move to the care home of their choice. The majority of the individuals (n=21) did not visit the care home prior to the move; one participant chose the home previously for his wife and one participant was accompanied by a social worker. The complete breakdown of care homes and participants’ moves are highlighted in **Table 4.1**. Participant characteristics, details surrounding the move to the care home, and participation in interview timepoints are outlined in **Table 4.2**.

**Table 4.1:** *Care homes and participant numbers*

<b>Home</b>	<b>Type</b>	<b>Participants (n)</b>
Home A	Urban Nursing Home Private 56 residents	4
Home B	Urban Nursing Home Private 28 residents	3
Home C	Urban Nursing Home Private 39 residents	3
Home D	Urban Nursing Home Private 70 residents	2
Home E	Urban Residential Home TRUST 27 residents	4
Home F	Rural Nursing Home Private 40 Residents	3
Home G	Rural Residential Home Private 45 Residents	2
Home H	Rural Residential Home TRUST 34 Residents	2

**Table 4.2: Participant Characteristics**

<b>Pseudonym</b>	<b>Age</b>	<b>Living arrangement prior to move</b>	<b>Stated reason for admission</b>	<b>Number of Interviews Completed</b>
Jane	84	Lived alone in rented accommodation	“Too old to be on my own and I’m frightened of falling”. Jane developed a chest infection was admitted to hospital, and then had poor mobility.	1,2,3,4
Ellen	82	Lived alone in rented accommodation	Husband died recently. In Hospital had a stroke. Wanted to move to sheltered housing Nursing Home was only available choice.	1,2,3,4
David	88	Lived alone in family home	Chose care home as wife already there a year previously. Health deteriorated after a fall at home “I’m too old to be on my own”	1,2,3,4
Bernadette	92	Lived alone in family home	Had fall at home admitted to hospital? “Family thought it was not right for me being on own. Mobility poor- “Doctor says move in”.	1,2,3,4
Sarah	84	Lived alone in rented accommodation	Health deterioration- admitted to hospital with chest infection -lost mobility. Domiciliary care support twice daily, was not working out.	1
Joseph	86	Lived with wife at home	Change in health-. “Losing my balance” Wife unable to meet his care needs.	1
Andrew	82	Lived alone in family home	Wife died. Had recent stroke. Was taken to hospital. Family overseas.	1,2,3,4
Martha	80	Lived alone at home	“Fell at home needed a new hip”. Changing family circumstances - no-one now at home.	1,2,3,4
Sean	60	Lived with wife and children in family home	Developed sepsis, progressed to paraplegia with lesion on spine. Total nursing care required. Facilities at home do not support nursing care.	1,2,3,4
Tracey	88	Lived alone in rented accommodation	Getting worried about deterioration in health or falling, chose residential care admission.	1,2,3,4
Charles	83	Lived with wife in rented accommodation	Wife died suddenly who was carer. Had been in a wheelchair for many years due to war injury. Admitted to care home via taxi on day of wife’s sudden admission to hospital. She died.	1,2,3,4

Molly	80	Lived alone in rented accommodation	"Developed anxiety". G.P advised admission "feeling safe now"	1,2,3,4
James	81	Lived with wife at home	Admitted to hospital with stroke and poor mobility. Wife unable to support care at home, due to mental ill health.	1
Anne	90	Lived alone in own home	Admitted to hospital with TIA. Then transferred to nursing Home - "no choice". Subsequently requested move from Nursing home to residential care - as "not that ill".	1,2,3,4
Isobel	96	Lived alone in rented accommodation	Chest infection admitted to hospital. Reduced mobility in hospital. Son working away.	1,2,3,4
Therese	78	Lived at home with brother and sister	Recent stroke. Sister and brother were "too old to care for me at home".	1,2,3,4
Francis	87	Lived alone in family home	Developed pneumonia and was admitted to hospital. G.P advised admission to care home.	1,2,3,4
Hugh	83	Lived alone in family home	Accident at home, admitted to hospital. Reduced mobility- niece lives far away and made arrangements for care home admission.	1,2,3,4
Mona	81	Lived at home with daughter	Poor mobility for many years. Daughter (carer) fell and injured back requiring hospital admission. Mona was taken to care home the same day. Both mother and daughter will require care home accommodation.	1,2,3,4
Kevin	83	Lived alone in family home	Fell while shopping. Taken to hospital. Staff advised residential care home admission.	1,2,3,4
Sophie	74	Lived with niece and nephew	Changing family circumstances following death of brother. Niece and nephew had ownership of house and "I'm no longer welcome".	1
Martina	81	Lived alone in family home	Deterioration in health and general mobility. "family all away and were frightened in case I should fall"	1
Philomena	73	Lived alone in rented accommodation	Getting old now and worried about being on own. Hoping for sheltered housing no places.	1

### **4.3 Sample**

It is recognised that even when researchers have successfully recruited older participants to a study, retention and attrition are common challenges due to study withdrawal, high mortality, comorbidity, hospital admissions, and transfers to another care facility (Van Ness *et al.* 2012; Wood *et al.* 2013). Participants in this study had moved to a care home and were aware that the move would be a permanent one. As outlined, twenty-three participants commenced the research study. At the second interview timepoint (four to six weeks post move), seventeen participants consented to partake in this interview. The study population was reduced by six participants, four females and two males. The reasons for non-participation at this time point were as a result of two untimely sudden deaths, two participants diagnosed as being terminally ill after the move and experiencing a rapid decline in health, one participant developing significantly reduced cognitive ability due to delirium, and one participant declining to continue with the second and any further interviews.

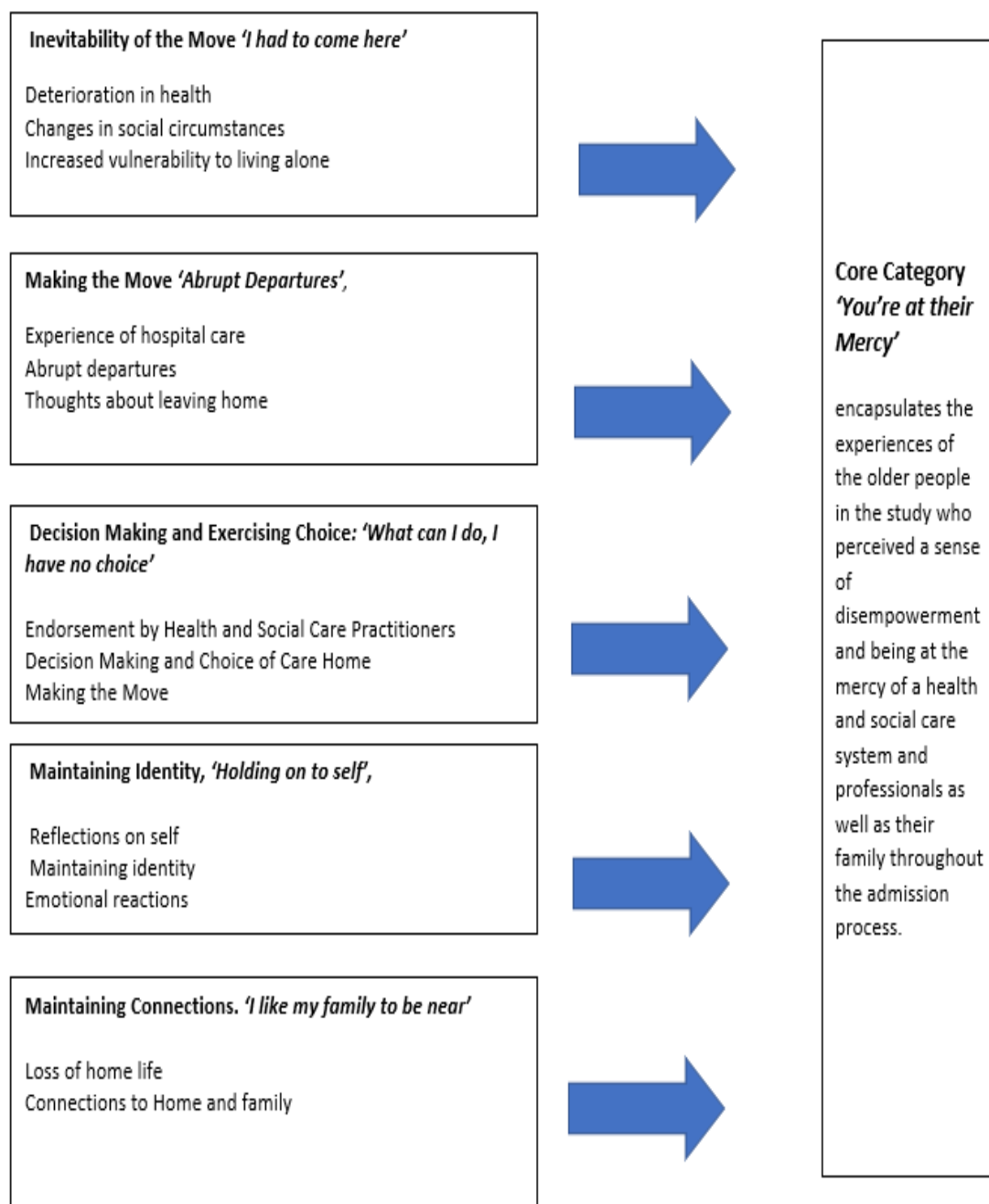
### **4.4 Interview One (Pre-move or immediate post-move)**

All interviews were conducted between April 2017 and August 2018. Semi-structured interviews were used to generate an in depth discussion aimed at illuminating the experiences and perspectives of participants who were transitioning to life in a care home. The interviews were conducted either in participants' homes, the care home or in a hospital setting while awaiting the move to a care home. The audio taped interviews were transcribed verbatim and lasted on average 60-90 minutes.

#### 4.5 Concepts, categories, and core category

All interview data were reviewed and when repeated ideas, concepts or elements became apparent, they were tagged with codes, which were extracted from the data. As more data were collected, and reviewed, codes were grouped into concepts, and then into categories. As analysis progressed, coding moved towards being “selective”, focusing on those codes which connected to emergent main categories. In the final stage of coding, the process of identifying and choosing the core category was undertaken by systematically connecting it to other categories and validating those similarities and relationships (Corbin and Strauss 2008). Five distinct categories were identified that captured the experience which were: 1) Inevitability of the Move: *‘I had to come here’*, 2) Making the Move: *‘Abrupt Departures’*, 3) Decision Making and Exercising Choice: *‘What can I do, I have no choice’* 4) Maintaining Identity: *‘Holding on to self’*, and 5) Maintaining Connections: *‘I like my family to be near’*. The core category ‘You’re at their Mercy’ depicts the experiences of the older people who identified a lack of decision making and autonomy with the move which in turn created a negative experience for some individuals causing emotional disturbance and personal loss. Moreover, maintaining continuity between the person’s past and present roles, and providing opportunities to form new relationships with other residents and staff were also considered important factors which contributed to the adaptation experience. Figure 4.1 shows the relationship of major categories to each other and to the core category.

**Figure 4.1:** Relationship of major categories to the core category

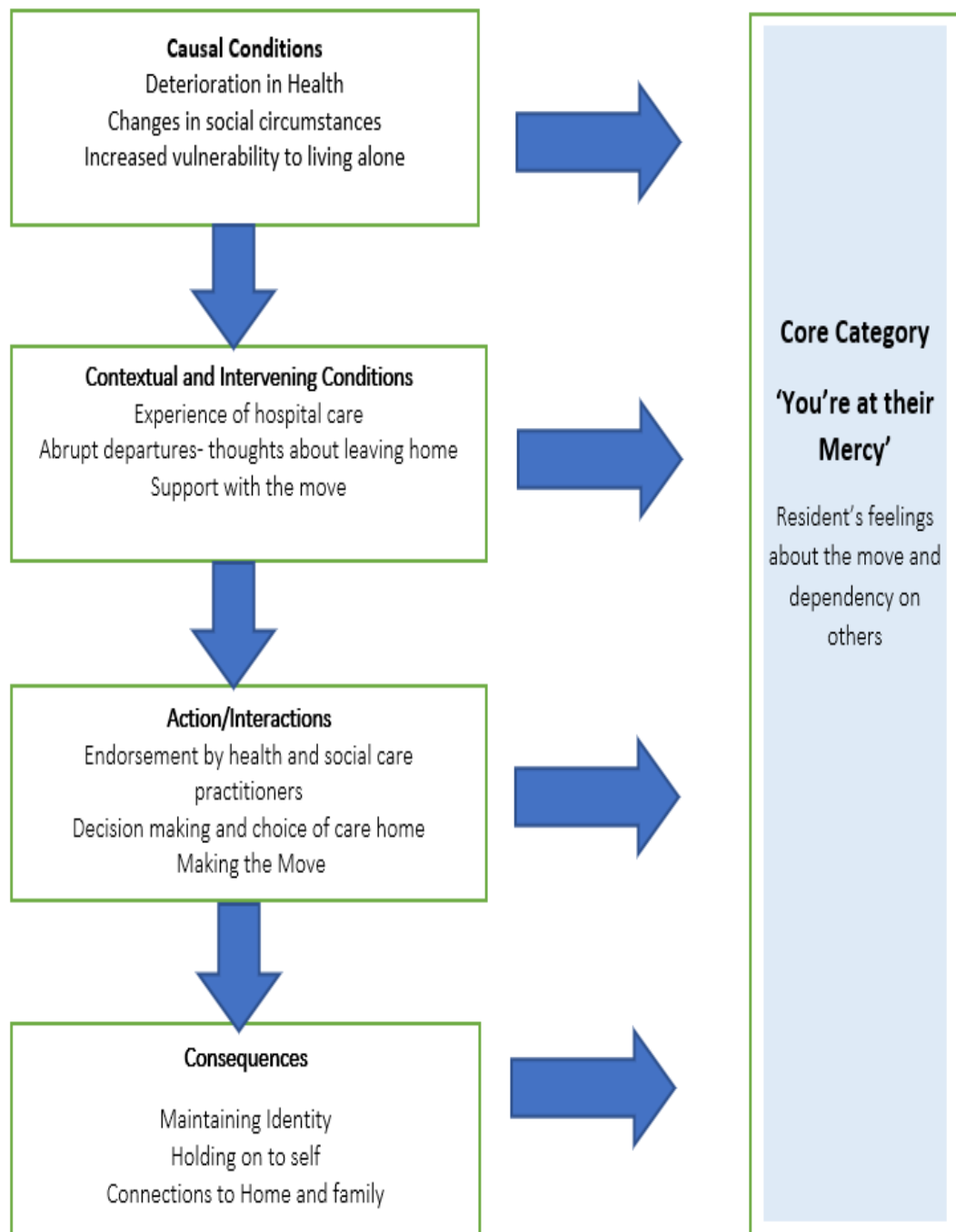




#### **4.6 Paradigm Model One**

The contextual and causal conditions for individuals making the move to the care home began with the series of events relating to their admission. These intervening conditions are interconnected to experiences of the specific circumstances of the move as evidenced within actions/interactions. Strauss and Corbin (2008) state that these actions/interactions are the ways or the 'how' by which individuals handle situations, demonstrating the connection to the core category. Being dependent on health care professionals is conceptualised within awareness of actions/interactions. Lack of decision-making and choice are linked to the core category and demonstrate the perceived 'being at the mercy' experience of individuals. Actions and interactions result in consequences which directly influenced individuals' reactions or non-reactions. The consequences at this time point were as a result of the actions/interactions which created a negative experience. This caused emotional disturbance and personal loss leading to individuals feeling anxious and 'at the mercy' of others during the move. In addition, concepts within the consequences category underpin the core category as individuals identified being 'at the mercy of others' to maintain independence and connections to their own identity, sense of self, family and home, Figure 4.2 the paradigm model for interview one.

**Figure 4.2: Paradigm Model One**



#### 4.7 ‘You're at their Mercy’: Older peoples' experiences of moving from home to a care home. (Paper ONE)

This paper reports key findings pertaining to the experiences of older people at the pre-move and immediate post-move phase of the relocation to care home. Identified categories were: 1) Inevitability of the Move: ‘*I had to come here*’, 2) Making the Move: ‘*Abrupt Departures*’, 3) Decision Making and Exercising Choice: ‘*What can I do, I have no choice*’ 4) Maintaining Identity: ‘*Holding on to self*’ and 5) Maintaining Connections: ‘*I like my family to be near*’. The core category ‘*You're at their Mercy*’ encapsulates the experiences of the men and women in the study who perceived a sense of disempowerment with the move. That is to say, the move and transition to a care home was perceived by participants to be out of their control; they were ‘at the mercy’ of others making the decisions and deciding their future including family members, social workers, community care managers and care home staff. In terms of choice or decision-making, or the actual move itself, there was little or no pre-planning. Neither was there a planned process of admission in which individuals were an active participant. Moreover, on arrival to the home they were at the mercy of others to maintain independence and connections to their own identity, sense of self, family, and home. A detailed discussion of these findings is presented in Paper one.

**Paper One:** O'Neill M, Ryan A, Tracey A and Laird EA (2020) “You're at their Mercy”: Older peoples' experiences of moving from home to a care home: A grounded theory study. *International Journal of Older People Nursing*, e12305. <https://doi.org/10.1111/opn.12305>

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## ORIGINAL ARTICLE

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# “You’re at their mercy”: Older peoples’ experiences of moving from home to a care home: A grounded theory study

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## Abstract

**Background:** Internationally, it is recognised that the transition to a care home environment can be an emotional and stressful occasion for older people and their families. There is a paucity of research that takes into consideration the initial phase of the relocation process, incorporating individuals’ experiences of the move.

**Aim:** To explore individuals’ experiences of moving into a care home. This paper has a specific focus on the preplacement (7 days) and immediate postplacement (within 3 days) period of the move to the care home.

**Design:** A grounded theory method was used to conduct semi-structured interviews with 23 participants.

**Results:** Data analysis revealed five distinct categories that captured the experience of the preplacement and immediate postplacement period. These were as follows: (a) inevitability of the move: “*I had to come here*,” (b) making the move: “*Abrupt Departures*,” (c) decision-making and exercising choice: “*What can I do, I have no choice*,” (d) maintaining identity: “*Holding on to self*” and (e) maintaining connections: “*I like my family to be near*.” Together, these five categories formed the basis of the concept “*You’re at their Mercy*” which encapsulates the perceived transition experience of the older people within the study. Participants felt that the move was out of their control and that they were “at the mercy” of others who made decisions about their long-term care.

**Conclusions:** Moving to a care home represents a uniquely significant relocation experience for the individual. Key factors influencing the move were the individuals’ perceived lack of autonomy in the pre- and postrelocating period of moving to a care home. Nurses have a key role to play in working with older people to influence policy and practice around decision-making, planning and moving to a care home with greater emphasis on autonomy and choice so that older people do not feel “at the mercy” of others as they navigate such a major transition.

**Implications for practice:** There is a need to standardise approaches and develop person-centred interventions to support older people considering relocation to a care home and nurses have a key role to play in making this happen.

## KEYWORDS

ageing, care homes, care of older people, decision-making, long-term care, older people, transition

## 1 | INTRODUCTION

The population of the world is ageing (World Health Organization, 2018a, 2018b), and internationally, there is an increasing trend for older people with complex care needs to reside in care homes. Within the United Kingdom (UK), there are approximately 17,678 care homes caring for 426,000 older people (Age UK, 2017). This figure represents 4% of the population aged 65 years and over, rising to 16% of those aged 85 or more.

It is recognised that the transition from living at home to living in a care home is a uniquely significant experience for older people that can be an stressful, challenging and an emotional event for individuals and families, as it involves a major adjustment in their daily lives (Brandburg, Symes, Mastel-Smith, Hersch, & Walsh, 2013; Cheek, Ballantyne, Byers, & Quan, 2007; Ellis, 2010; McCarthy, 2016; Ryan & McKenna, 2015; Sury, Burns, & Brodaty, 2013). Relocation to a care home normally occurs at a point in life when an individual is at an advanced age with increasing likelihood of multi-morbidities and dependency (Barnett et al., 2012; Marengoni et al., 2011; Ryan & McKenna, 2015).

The transition experience includes the decision-making process, planning process and preparation of the older person and their family (Lee, Simpson, & Froggart, 2013). Numerous factors including health and social issues can influence the adaption and adjustment process for older people when relocating to a care home (Bradshaw, Playford, & Riaz, 2012; Brownie, Horstmanshof, & Garbutt, 2014; Križaj, Warren, & Slade, 2018). Additionally, there were heightened feelings of loneliness and isolation when the care home admission was unplanned and not discussed with the resident (Bowers, Nolet, & Jacobson, 2015; Brownie et al., 2014; Thein, D'Souza, & Sheehan, 2011).

The transition process begins before the move into the care home, and the extent to which residents can exercise control over the decision to move from their home to a care home is recognised as an important determinant of their relocation experience (Chao et al., 2008; Fraher & Coffey, 2011; Johnson, Popejoy, & Radina, 2010; Lee et al., 2013; Ryan & McKenna, 2015). Moreover, individuals reported that having greater involvement could have eased the negative feelings surrounding the move (Nwe, D'Souza, & Sheehan, 2011; Sury et al., 2013). Residents admitted to care homes 'against their will' and those who felt that they 'had no choice' were more likely to experience sadness, depression and anger compared with those individuals who relocated willingly (Brownie et al., 2014; Fraher & Coffey, 2011; Johnson et al., 2010; Ryan & McKenna, 2015). It is known that good communication can enhance the move for residents and families, allowing them to feel confident in their decisions, able to ask questions and make suggestions without fear of repercussions. On the other hand, poor communication can lead to uncertainty, worry and anxiety (Graneheim, Johansson, & Lindgren, 2014; Ryan & McKenna, 2015).

### What does this research add to existing knowledge in gerontology?

#### What is already known about the topic?

- It is recognised that the transition to long-term care can be an emotional and stressful event for older people.
- Numerous factors including health and social issues can influence the adaptation and adjustment process for older people when relocating to a care home.
- The extent to which residents are able to exercise control over the decision to move from their home to a care home is recognised as an important determinant of their relocation experience.

#### What this paper adds?

This study identifies that:

- There was a perceived lack of autonomy for most individuals in their decision to move to a care home, and in having a choice in the selection of the care home.
- The lack of participation in decision-making and choice about the move created a negative experience causing emotional disturbance and personal loss leading to individuals' feeling anxious and at the mercy of others during the move.
- The importance of bringing a sense of home and possessions to the care home environment is highlighted, as having a significant psychological and emotional impact on the individual.

#### What are the implications of this new knowledge for nursing care with older people?

- There is a need to standardise approaches and develop person-centred interventions to support older people considering relocation to a care home and nurses have a key role to play in making this happen.
- Best practice policy directives on moving to a care home should include the development of auditable guidelines to include equal access to health and social care services post-transition.
- Future research should include the perspective of healthcare professionals involved in supporting older people in making the move to care homes.

#### How could the findings be used to influence policy or practice or research or education?

- Nurses have a key role to play in working with older people to influence policy and practice around decision-making, planning and moving to a care home with greater emphasis on autonomy and choice so that older people do not feel "at the mercy" of others as they navigate such a major transition.
- Nurses and other healthcare professionals must work in partnership with older people to support and empower them to plan for the future when deciding on their own long-term care needs.
- This study highlights the need to make decisions about relocating to a care home in partnership with older people and has the potential to inform policy and practice.



Older people are often not involved in research processes even when studies are care-home-focused (Backhouse et al., 2016). Some studies that have focused on the decision-making processes surrounding the move have highlighted that older adults rarely initiate relocation decisions relying instead on family, professionals or both to determine when relocation is called for (Fraher & Coffey, 2011; Keister, 2004; Reed, Cook, Sullivan, & Burrige, 2003). Moreover, the processes involved in moving to a care home from home or following acute hospitalisation are still poorly investigated and there is a paucity of research that takes into consideration the relocation experience with a focus on the preplacement and immediate postplacement phase of the move. This study aimed to address the dearth of research in this area. It is predicted that the knowledge gained will inform care delivery in determining the nature of ongoing support needed by individuals at this critical time point in their transition to life in a care home.

## 2 | DESIGN AND METHOD

Adjustment to care home life is a process that occurs over a period of time. Part of understanding this process requires recognition of variances in the experiences of older adults whose permanent move to a care home was either planned or unplanned. A grounded theory approach, consistent with the work of Strauss and Corbin (1990, 1998), was therefore chosen as it facilitated the development of a new perspective on the phenomenon of entry to long-term care. Consistent with grounded theory methodology, the overall aim of this study was to explore individuals' experiences of moving into a care home with a specific focus on the preplacement (7 days) and immediate postplacement (within 3 days) period of the move to the care home.

### 2.1 | Data collection

Semi-structured interviews were utilised to collect data from 23 individuals who were due to move to a care home on a permanent basis between April 2017 and August 2018. As outlined in Table 1, most of the participants were female ( $n = 14$ ). Semi-structured interviews were utilised as they provided both focus and flexibility, consistent with Strauss and Corbin's grounded theory method. This approach also facilitated the process of constant comparison, a key cornerstone of grounded theory methodology. Purposive sampling was adopted in the initial phases of data collection, and thereafter, theoretical sampling was employed. The initial selection criteria stipulated that participation in the study was confined to individuals who (a) were due to move to a care home on a permanent basis; (b) were within one week of moving into the care home; and (c) minimal or no cognitive impairment as defined by the Mini Mental State Examination (MMSE > 24) (24 or over). A one-week "cooling-off period" was given to participants after which time the researcher contacted them again to confirm their willingness to take part in the study and to arrange consent prior to undertaking first interview. However, accessing the

sample within a week prior to the move proved to be problematic due to pressures on staff to free up hospital beds and fill care home places. This meant that once the funding was approved for the care home bed, individuals awaiting such beds were often transferred within 2–3 days, and in some cases, preadmission assessments were being undertaken by care home staff on the morning of the older person's admission to the care home. While this issue further highlighted the importance of exploring this particular time point in the transition to life in a care home, it became clear that we would not be able to recruit the numbers we required. We therefore revised our selection criteria to enable us to recruit individuals within one week before and after the move to the care home and obtained ethical approval to revise "cooling-off period" to one day after which time the researcher contacted them again to confirm their willingness to take part in the study and to arrange consent prior to undertaking interview. Of the 23 participants recruited to partake in the study, six were interviewed in hospital, five at home and 12 within three days of admission to the care home. Of these 12 care home participants, two had interviews on day 1, seven on day 2 and three on day 3; thus, individuals were "very new" to the care home environment.

Participants were recruited through social workers within older people's community teams and by waiting lists held by care home managers within a large Health and Social Care Trust in the UK. The Trust provides health and social care services to a population of approximately 300,000 people. The care homes ( $n = 8$ ) were registered with the Regulation and Quality Improvement Authority and were located within both rural and urban care facilities. Full ethical approval to conduct the study was granted by the University Research Ethical Committee, the Office of Research and Ethics Committee, Northern Ireland and the Health and Social Care Trust where the study was carried out. The interviews occurred at a time and place convenient for participants and theoretical sampling continued until the emerging concepts and categories reached saturation.

### 2.2 | Data analysis

Consistent with grounded theory methodology, data collection and analysis occurred simultaneously. Constant comparative analysis underpinned data analysis and data management techniques. Participants gave consent for the recording and transcribing of interviews. NVivo 12 qualitative data analysis software program (QSR International, 2018) facilitated the organisation, management and retrieval of transcribed interviews and field notes and provided tools for coding, categorising and linking qualitative data (Bazeley, 2013). Two researchers reviewed all the data collected. Repeated ideas, concepts or elements became apparent and were tagged with codes extracted from the data. Grouping of codes into concepts and then into categories was undertaken after more data collection and review. As analysis progressed, coding moved towards being "selective," focusing on those codes that related to emergent main categories. In the final stage of coding, the process of identifying and choosing the central concept occurred by systematically connecting it to other

TABLE 1 Characteristics of the Interviewees

Pseudonym	Age	Living arrangement prior to move	Reason for admission	Location of interview (Time point)
Jane	84	Lived alone in rented accommodation	"Too old to be on my own and I'm frightened of falling." Jane developed a chest infection was admitted to hospital and then had poor mobility.	Hospital (preplacement)
Ellen	82	Lived alone in rented accommodation	Husband died recently. Wanted to move to sheltered housing nursing home was only available choice.	Nursing home (postplacement Day 1)
David	88	Lived alone in family home.	Chose care home as wife already there a year previously. Health deteriorated after a fall at home "I'm too old to be on my own"	Hospital (preplacement)
Bernadette	92	Lived alone in family home.	Had fall at home admitted to hospital? "Family thought it was not right for me being on own." Mobility poor—"Doctor says move in."	Home (preplacement)
Sarah	84	Lived alone in rented accommodation.	Health deterioration—admitted to hospital with chest infection—lost mobility. Domiciliary care support twice each day was not working out.	Hospital (preplacement)
Joseph	86	Lived with wife at home	Change in health—"Losing my balance." Wife unable to meet his care needs.	Nursing home (postplacement Day 2)
Andrew	82	Lived alone in family home	Wife died. Had recent stroke. Was taken to hospital. Family overseas.	Nursing home (postplacement Day 2)
Martha	80	Lived alone at home	"Fell at home needed a new hip." Changing family circumstances—no one now at home.	Home (preplacement)
Sean	60	Lived with wife and children in family home	Developed sepsis, progressed to paraplegia with lesion on spine. Total nursing care required. Facilities at home do not support nursing care.	Nursing home (postplacement Day 2)
Tracey	88	Lived alone in rented accommodation	Getting worried about deterioration in health or falling, chose residential care admission.	Home (preplacement)
Molly	80	Lived alone in rented accommodation	"Developed anxiety." G.P advised admission "feeling safe now."	Residential home (postplacement Day 3)
Charles	83	Lived with wife in rented accommodation	Wife died suddenly who was carer. Had been in a wheelchair for many years due to war injury. Admitted to care home on day of wife's death in a taxi.	Nursing home (postplacement Day 1)
James	81	Lived with wife at home	Admitted to hospital with stroke and poor mobility. Wife unable to support care at home, due to mental ill health.	Nursing home (postplacement Day 3)
Ann	90	Lived alone in own home	Admitted to hospital with TIA. Then transferred to nursing home—"no choice." Subsequently requested move from nursing home to residential care—as "not that ill."	Residential home (postplacement Day 2)
Isobel	96	Lived alone in rented accommodation	Chest infection admitted to hospital. Reduced mobility in hospital. Son working away.	Home (preplacement)
Therese	78	Lived at home with brother and sister.	Recent stroke. Sister and brother were "too old to care for me at home."	Hospital (preplacement)
Francis	87	Lived alone in family home.	Developed pneumonia and was admitted to hospital. G.P advised admission to care home.	Residential home (postplacement Day 2)
Hugh	83	Lived alone in family home	Accident at home, admitted to hospital. Reduced mobility—niece lives far away and made arrangements for care home admission.	Hospital (preplacement)
Mona	81	Lived at home with daughter	Poor mobility for many years. Daughter (carer) fell and injured back requiring hospital admission. Mona was taken to care home the same day. Both mother and daughter will require care home placement.	Hospital (preplacement)

(Continues)

TABLE 1 (Continued)

Pseudonym	Age	Living arrangement prior to move	Reason for admission	Location of interview (Time point)
Kevin	83	Lived alone in family home	Fell while shopping. Taken to hospital. Staff advised residential care home admission.	Residential home (postplacement Day 2)
Sophie	74	Lived with niece and nephew	Changing family circumstances following death of brother. Niece and nephew had ownership of house and "I'm no longer welcome."	Residential home (postplacement Day 3)
Martina	81	Lived alone in family home	Deterioration in health and general mobility. "family all away and were frightened in case I should fall."	Home (preplacement)
Philomena	73	Lived alone in rented accommodation	Getting old now and worried about being on own. Hoping for sheltered housing no places.	Residential home (postplacement Day 2)

categories and validating those similarities and relationships (Corbin & Strauss, 2008). The concept of "*You're at their mercy*" emerged from the final analysis. Using the framework recommended by Strauss and Corbin (1990, 1998), Figure 1 shows how the paradigm model is developed to represent the findings that emerged from this study.

### 2.3 | Ensuring Rigour

Various strategies were utilised to ensure the rigour of the study. The study was conducted with an awareness and application of the underlying principles of the authenticity criteria developed by Nolan, Hanson, Magnusson, and Anderson (2003) and further developed in care homes research by Wilson and Clissett (2011). Equal access promoting accessible and comprehensive information to all participants about the nature of their involvement with the study was given. In the grounded theory approach, validity depends on theoretical sensitivity, which refers to the ability to give meaning to data and the capacity to understand the sources of theoretical sensitivity (Strauss & Corbin, 1990). The initial interviews were recorded and checked to ensure the rigour of the data collection procedures. No formal member checking was performed within this study; however, the constant comparison of emerging data facilitated the verification of findings and minimised the likelihood of personal bias. As data collection proceeded and the basis of a theory began to emerge, it became necessary to theoretically sample older people in residential and rural care homes as interim findings would indicate something different about the experiences of older people in care homes within an urban environment. Strauss and Corbin (1998) have described theoretical sampling as a means to "maximise opportunities to discover variations among concepts and to densify categories in terms of their properties and dimensions" (p. 201). Therefore, potential participants moving to these types of care homes were invited to take part in the study. Similarly, if individuals mentioned anything that was considered to be of interest, this was followed up in subsequent interviews. The process of theoretical sampling continued until the emerging concepts and categories reached saturation. Repeatedly emerging concepts and categories were thought to have high levels of truth and value, while concepts

and categories that were not verified by subsequent data were considered to be lacking in truth and consistency. During the open and axial coding stages, two members of the research team independently viewed the original uncoded manuscripts and confirmed themes, thus ensuring that interpretations represented the experiences of the individuals. After the selective coding process, four members of the research team enhanced trustworthiness of the data by meeting to discuss the emerging themes and these themes were reviewed and revised as needed. Therefore, interpretations of the data were seen as credible, dependable and confirmable (Lincoln & Guba, 1985).

### 2.4 | Profile of participants

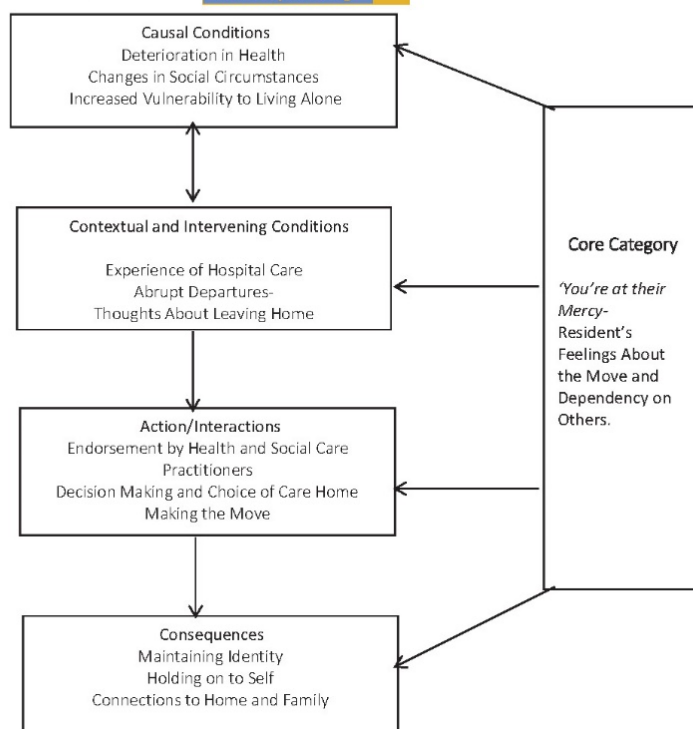
The twenty-three participants in this study comprised of fourteen females and nine males with an average age of 82.4 years. Thirteen participants were admitted directly from hospital. Six of these individuals were female and seven were male. In comparison, eight female and two male participants were admitted to the care home directly from home. The majority of the individuals ( $n = 14$ ) were living alone at the time of admission (hospital/care home), while the remaining nine participants lived with spouse/family members. Of the nine that were living with spouse/family, five reported that community care services could no longer meet their needs.

The main reasons cited for prompting the relocation to a care home were deterioration in physical health ( $n = 17$ ), recent bereavement ( $n = 3$ ) and no one to take care of me/changing family circumstances ( $n = 3$ ). Only four of the individuals had made the decision to move to a care home, and of these four, only two were able to move to the care home of their choice.

## 3 | FINDINGS

This paper reports key findings pertaining to the experiences of older people at the preplacement and immediate postplacement phase of the relocation to care home. Identified categories were as follows: (a) inevitability of the move: "*I had to come here*," (b) making the move:





**FIGURE 1** Residents' experiences of moving from home into a care home—a grounded theory conceptual paradigm model illustrating relationship of major categories to each other and to the core category

"Abrupt Departures," (c) decision-making and exercising choice: "What can I do, I have no choice," (d) maintaining Identity: "Holding on to self" and (e) maintaining connections: "I like my family to be near." The concept "You're at their Mercy" links the identified five categories and encapsulates the experiences of the older people in the study who perceived a sense of disempowerment and being at the mercy of a health and social care system and professionals as well as their family throughout the admission process. Moreover, on arrival to the home they were at the mercy of others to maintain independence and connections to their own identity, sense of self, family and home.

Changes in health, social circumstances such as a carer becoming unwell or dying, and an increased vulnerability to living alone were predictors of the move to a care home.

*Well to tell you the truth I wasn't going to do another winter on my own at home. Well I said to Dr X that I wasn't great, and he got me in here. I used to be able to walk anywhere 7 days a week do you know how much I can walk now .... about 10 minutes then I am done*

(Francis)

### 3.1 | From concepts to categories

#### 3.1.1 | Inevitability of the Move: "I had to come here"

The admission to a care home was a unique experience. For a minority, it was a planned process with active participation, and for others, it was challenging and complex. Healthcare professionals, especially GPs, social workers, hospital staff and care home managers, were frequently described by individuals as very influential in the decision-making process. Moreover, the data conveyed a sense of the inevitability of the move.

*I had to come here as I have been on my own a long time since my husband died and I suppose finding things more difficult. My sister would be worried about me you see, her and my daughter. They convinced me that maybe a residential home would be a good place for me as I could come and go as I please*

(Philomena)

The move took on a sense of inevitability as care and "hands on support" needs increased in tandem with decreasing health and physical capabilities.

*Well I had a bad fall a few months ago and I wasn't really myself after that. I lost my confidence and of course they worried away about me and wanted to make sure nothing happened to me. You know you can't do this on your own. You have to have help. So that's where I am*

(Tracey)

*So, I knew then after this fall that I would not be able to go back again. You know with the stairs and all and different things like that. I think that it was a good decision that I made you know*

(Kevin)

The circumstances surrounding an individual's admission to a care home were rarely ideal. The person may have had several previous hospital visits, and perhaps a more recent deterioration in their health that left them unable to care for themselves at home. When combined with little or no family support, a care home was seen as the only choice.

*I have really bad arthritis now and I would have bother getting about you know on my own with no family. You feel as you get older everything starts to fail...it gets worse*

(Jane)

*Well I had sicknesses, two operations on my hip, and that's why I can't walk very well, and I had this thing with falling. They came and took me to Hospital and that was it no more going home for me on my own the social worker said, I am here now*

(Ellen)

### 3.1.2 | Making the move: "Abrupt Departures"

Many individuals in the study reported that the move to the care home was often a rushed and a hasty affair regardless if it was from the hospital or their own home.

*Well the same day the nurse in the hospital told me I was not going home the carers from the home came and got me from the hospital and took me here*

(James)

*I came from home as an emergency the day my wife took sick, she had a stroke and died in hospital. I had to come here. I had no choice about coming here and the social worker said that staying on my own was not an option... I was put in a taxi with no shoes on my feet and brought here*

(Charles)

Many individuals in the study spoke about how care managers/hospital staff are the key people making the decisions about moving to care home, often very quickly once they received confirmation of bed availability.

*When the bed becomes available well that's it, apparently you have to grab it. The sad thing for me about moving to the care home tomorrow is that I'm walking in a dead man's shoes!*

(David)

*So really you are at the mercy of other people and the health care system, aren't you?*

(Sean)

During the recruitment process, the researchers took cognisance of care managers who reported that once financial funding became available for a care home placement, the transfer of older people to a care home occur very quickly thereafter. This had repercussions for undertaking the first interview prior to admission to the care home. The following theoretical memo offers insight into the experiences of care home managers.

#### 24.04.17

Care home managers have reported that on frequent occasions they were asked to undertake a patient care assessment in the morning and due to the pressures of freeing up hospital beds were asked to accommodate having the older person move to the care home that very evening. This left managers feeling pressurised and frustrated that individuals were not getting time to prepare for the relocation to a care home.

### 3.1.3 | Decision-making and exercising choice: "What can I do, I have no choice"

The data conveyed that only three individuals had been able to exercise some choice in the care home they moved to:

David explained that "I chose this nursing home for my wife. She is here, and I liked what I saw."

Tracey related "I got a social worker through the G.P. They ask you what you think of all the different ones you know. So, you tell them what you think and that's it. I just looked at two homes that was the choice. I think it's very good here," and.

Therese stated "Well I wanted to come here as I was here a few years ago for a couple of weeks when I had surgery (pause)... but it was good then, I liked it, but it is not the same now."

For some individuals, there was no offer or choice to stay at home with increased support. Personal control and level of engagement in

decision-making processes appear to have been guided by health-care staff and family.

*I didn't really have a say in where I would go, it was the social worker talking to my family, they arranged it all*

(Ann)

*The doctor said I needed to come in here. What can I do, I have no choice? I couldn't go home unless I was able to go home, like if I was fit or had proper care at home*

(Therese)

*My brother had left instructions that I was to be looked after... but it didn't work out like that... How would you like to be put in a home against your will?*

(Sophie)

*Well the family arranged all this... not my choice*

(Martina)

The small "window of opportunity" to obtain a care home "bed" when one became available further restricted choice. Individuals conveyed an understanding of having to "take the next one available."

*My niece was responsible for me coming here, that's the way it was, the pressure was put on her to get me a home quickly so that is why I am here. All these places are all filled up you see.*

(Hugh)

For individuals who were receiving care in acute hospital services, there were additional pressures to "move on" and "free up beds."

*I didn't know about this place at all. In the hospital they were looking to get the bed released and we had to start looking for a care home, but they were all filled up. The pressure was put on us you see so under the circumstances I had to come here and take the first place that came up.*

(Jane)

*You don't have much choice, most of them are full, that's the problem, and this was the only one I could get. I never heard of it and I never got to see it. I wanted to live in sheltered housing*

(Ellen)

Another factor that appeared to influence the choice of care home was "age." After admission to hospital for an extended period following the development of sepsis and paralysis, Sean needed 24-hr care upon transfer to the care home. In Sean's locality, there was only one care home that accommodated residents under the age of 65 years.

*I came here because there was nowhere for me to go. This is the only home that takes people like me under 65 in this area. I had no choice I couldn't comprehend any of this, on me and on my family and it took a while for us to get used to what had happened. I'm still not 100% about coming here.*

(Sean)

### 3.1.4 | Maintaining identity: "Holding on to self"

The importance of maintaining continuity between past and present roles and relationships was seen as an important element of future adaptation to life within a care home, encouraging the individual's self-esteem and personal identity. A major challenge associated with the transition into a care home was the perceived loss of the individual's home life, therefore threatening identity, belonging and sense of self.

*I wouldn't feel like myself here. The farm is my life so that is where I want to be every day. You never retire being a farmer you know it is in your blood... a way of living*

(Joseph)

Another individual spoke about her feelings of sadness at moving into a care home but worried about expressing this anxiety about the move to others.

*It's a very sad time for me just now you know. But I mean other people are just getting on with it... people don't talk about their own bothers... they help everybody else instead. So, I don't know whether I'm right or wrong staying quiet*

(Tracey)

Despite the unsettling nature and anxiety-provoking contexts of getting to know residents and staff, efforts were utilised to project self-agency and resilience.

*The future... you don't have much choice being in here but I'm holding on, I'm trying to fit in*

(Andrew)

*Look love I am here now, I've arrived. There is no going back home. I have to put up with it so there is no point in*

*me talking about it anymore. I just need to get on with it now". I don't want to talk about it*

(Martina)

The importance of supporting independence for sense of identity was emphasised. There was frustration expressed that care home staff were preventing them from doing the things they wanted to or were taking their independence away by doing things for them that they were able to manage themselves.

*I'm trying to get my power assisted wheelchair here, so I can get about myself. This is not a big thing...but once they hoist you into that chair, you're at their mercy for them to take you somewhere*

(Sean)

*I am not angry I am just annoyed that they can't get it right. The hospital told them that I needed to have physio to get me walking more and nothing has happened since I have arrived... apparently, it all takes time to organise... Not much good if you have had a stroke and you have to keep moving... they don't tell me what to expect or what is happening.*

(Andrew)

On arrival at the care home, some individuals felt that they were incorrectly placed in their particular care home. For these individuals, the care home environment and care provided were perceived as not meeting their needs. For one individual, this sense of mismatch prompted her to discuss other options with the social worker. In her case, this action prompted a rapid move from the nursing home to a residential home.

*I couldn't sit in a big room with a whole lot of people looking at TV all day and no-one talking. I didn't want to be like that or turn into something that I wasn't. And even in that big room the poor souls would all fall asleep. And I thought you know I'm just not suited to this at all. Restriction, it's a big thing isn't it? When I came around to saying to the social worker that the home wasn't for me, she agreed this residential home was more suitable and here I am*

(Ann)

### 3.1.5 | Maintaining Connections: "I like my family to be near"

Individuals talked about the positive contribution family visits and old friendships would make towards maintaining a sense of connectedness between their past life at home and life in a care home.

*My family come in and that makes a difference*

(Joseph)

*There's not much to look forward to now I'm here. I mean I look forward to seeing people belonging to me coming in*

(Isobel)

*I'm too old to be thinking of things. I know that I like peace and I like my family to be near*

(Jane)

It was important for individuals to maintain their role as father, mother, sister and brother. One individual Andrew had a schedule of family visits lined up from children who were living in other countries.

*My children are all away. They have made a pact that one of them will come over every month to see me for a few days. My son is coming this week*

(Andrew)

Although some participants had just moved to the care home, they reported being dependent upon care home staff and family to get outdoors and maintain continuity with home and the community. Getting a care home near to home was important in maintaining a sense of well-being. If participants were able to continue corresponding with friends and families, it gave them a sense of control and enabled them to maintain the relationships. One individual spoke about her "delight" at getting a care home placement which was near to her family and one where she had previously visited friends and had undertaken some social and recreational activities with them and where she felt "at home."

*When I came here, they were all throwing their arms round me here because they all knew me from visiting other residents, so I felt so welcome. I hope to be going out with my cousin to Mass fairly soon when the weather improves. She wants to take me up home afterwards and it would be nice to go you see I will miss that every week now.*

(Ann)

## 4 | DISCUSSION

This study set out to explore older peoples' experiences of the pre-move or immediate postmove transition to a care home. Nine males and fourteen females aged between 60 and 94 years were interviewed at their respective home, hospital environment or within three days of arrival at the care home. Given the paucity of research concerning such a transition (Armstrong, Hamilton, & Shenkin, 2014; Davies & Nolan, 2006; Sussman & Dupuis, 2012), the aim was to gain insights into the nature of the relocation and to discover more about



the experiences of older people before and immediately after the move to a care home.

Five distinct categories captured the experience of the preplacement and immediate postplacement period: inevitability of the move, making the move, decision-making and exercising choice, maintaining identity and maintaining connections. The concept "You're at their mercy" encapsulates the experiences of the older people within the study. Participants perceived that the move to a care home was out of their control; they felt "at the mercy" of others in the decision-making process. Being at the mercy of someone is defined by the Cambridge Dictionary (2019) as "to be in a situation where someone or something has complete power over you." The older people in this study appeared to see themselves as being powerless as a result of others, for example family members, social workers, community care managers and care home staff, making decisions on their behalf. Closely linked to their feelings of being at the mercy of others was the strong sense of disempowerment that permeated the experiences of most of the older people in this study. In the absence of any opportunity or encouragement to have their voice and choice heard, they appeared to display a resigned acceptance to their fate. These findings concur with international literature that reports moving to a care home as being a traumatic and life-changing experience for older people. Often, the importance of moving to a care home is not recognised or supported by formal services (Brownie et al., 2014; Cooney, 2012; Thein et al., 2011). Moreover, international studies show that poor communication and a lack of voice, choice and control can adversely affect transition experiences (Dossa, Bokhour, & Hoening, 2012; Fuji, Abbott, & Norris, 2012; Hanratty et al., 2012; Toles, Abbott, Hirschman, & Naylor, 2012).

#### 4.1 | Management of the move

It is evident from the literature that a more successful transition or adjustment to a care home is associated with a planned admission rather than unplanned admission (Gilbert, Amella, Edlund, & Nemeth, 2015; Walker & McNamara, 2013). In terms of choice, collaboration or the actual move itself, there was little or no preplanning. Neither was there a planned process of admission in which individuals were an active participant. Such was the extent of unpreparedness, Charles reported being "put in a taxi" unaccompanied late at night, while his wife who was his main carer was under transfer to hospital as an emergency (she died shortly afterwards). For many individuals, there was little opportunity to plan or consider which possessions they could be taking into the home. As a result, personal belongings were brought in by family/friends/neighbours or indeed from social workers under the instruction of the individual either from a hospital bed or within the first few days of arrival to the care home. In the case of Charles, he had no opportunity to bring "clothes, money and a few bits and pieces of sentimental value." In adapting to new surroundings, the importance of bringing a sense of home and possessions to the care home environment is highlighted, as leaving behind the previous home and possessions can have a

significant psychological and emotional impact (Cooney, 2012; Falk, Wijk, Persson, & Falk, 2013; Marshall & Mackenzie, 2008). This lack of involvement in decision-making was borne out of a service-driven necessity "to free up hospital beds," placing individuals irrespective if they were at home or in hospital in "the next available" care home bed no matter where the location. Both Ellen and Philomena identified a wish to move to sheltered housing accommodation but were placed into a nursing home, and Ann requested to be moved from nursing to residential care as "I wasn't that ill." Due in part to the "urgent nature" of the moves and lack of preparation and planning, those participants interviewed within three days of arrival to care home reported comparable responses to those participants interviewed in hospital or in their own home. Relinquishing control and not being involved in the decision-making process leads to feelings of fear and anxiety, while having greater involvement could have helped to ease the negative feelings surrounding the move (Nwe et al., 2011; Sury et al., 2013). The management of the move is contrary to the recommendations of Sussman and Dupuis (2014), who highlighted the ideal stages of planned admission to a care home environment as the decision to move, premove preparation and moving day circumstances. In this study, the expeditiousness of admission is driven by several factors including changes in health, social circumstances and increased vulnerability to living alone. The reasons for moving into a care home were challenging and complex and indeed often fraught with difficulties, not least because of the lack of involvement in decision-making about care home entry and individual care home placement or location.

#### 4.2 | Decision-making and Autonomy

While it is recognised that decisions about long-term care should not have to be made by people in crisis (National Institute for Health and Care Excellence (NICE) 2015) (NICE), the findings suggest that lack of participation in decision-making and choice about the move created a negative experience for some individuals causing emotional disturbance and personal loss, and these findings are acknowledged internationally (Fraher & Coffey, 2011 (Ireland); Johnson et al., 2010 (USA); Lee et al., 2013 (UK) & Zamanzadeh, Rahmani, Pakpour, Chenoweth, & Mohammadi, 2016 (Iran)). Imposing an unplanned or emergency admission left individuals feeling "lost" and isolated leading them to feel anxious and uncertain as they entered a new environment (Koppitz et al., 2017).

Notwithstanding the complexity of care home admissions, this study has found that for some individuals an increased sense of self was evident if they initiated the decision to move on their own terms. While there were those who felt that the decision to move to a care home was out of their control or made on their behalf, a few individuals did acknowledge the realisation that perhaps the move was necessary and again this is endorsed previously within the literature (Graneheim et al., 2014; Nwe et al., 2011). There is evidence to suggest that a person will perceive their relocation more positively when introduced to a care home prior to the move

(Graneheim et al., 2014; Sury et al., 2013; Sussman & Dupuis, 2014). This is supported by Ryan and McKenna (2015) who found that "familiarity" emerged as the core category influencing rural family carers' experience of the nursing home placement of an older relative.

International research literature (Brownie et al., 2014; Cooney, 2012; McKenna & Staniforth, 2017; Thein et al., 2011) shows the importance to older people of retaining autonomy in their lives and of feeling valued and purposeful. Our study has uncovered the lack of autonomy that older people experience pre- and postrelocating to a care home. A human rights approach to decision-making would respect older people's autonomy by genuinely involving them in defining their own care needs. The World Health Organization advocates that international health systems should be organised around older people's needs and preferences, designed to enhance older peoples' intrinsic capacity and integrated across settings and care providers (World Health Organisation, 2015). Commissioning bodies have significant scope to influence the way care services are organised and delivered and can stipulate specific practice and outcomes aimed at protecting and promoting human rights. Nursing and healthcare staff must follow policy directives, guidelines and recommendations for best practice in relation to respecting autonomy and choice for older people. By implementing a human rights-based approach, healthcare professional can empower older people to know and claim their health and social care rights, therefore increasing the accountability of individuals and institutions responsible for respecting, protecting and fulfilling the rights of older people. These core elements of advocacy underpin person-centred approaches to care (McCormack & McCance, 2017; Phelan et al., 2017). From an educational perspective, the findings suggest the need for nurse educators to equip future nurses and healthcare professionals with the knowledge, skills and attitudes to work in partnership with older people, promoting autonomy and choice and challenging systems and approaches that are system-focused, ageist and disempowering to older people.

#### 4.3 | Ageism and stereotypical views of older people

Despite the growing numbers of people who present with complex health and social care needs, internationally, healthcare systems continue to deliver care that is medically orientated (Kuluski, Ho, Hans, & Nelson, 2017). A service-led approach to health and social care has meant that individuals are expected to fit in with the services provided. The findings from this study clearly show that there was a lack of autonomy for many individuals in their decision to move to a care home, nor in having a choice of the care home. This study is unique because the data are collected in the prerelocation time period, or the early postrelocation phase. The authors have not identified any previous studies on transition to care homes that have collected qualitative data that explored

experiences and perspectives of older people at this important tight time frame. Globally, moving home is known to be a major stressor in the lives of adults (Brandburg et al., 2013; Cheek et al., 2007; Ellis, 2010; Ryan & McKenna, 2015), and even more so, when people's views and perspectives are not informing the change (Brownie et al., 2014; Thein et al., 2011). Disregard for people's views and opinions can predicate towards maladaptation to new social circumstances (Bradshaw et al., 2012; Brownie et al., 2014; Križaj et al., 2018).

It is very disconcerting to find that in the 21st century, most older people within this study had such negative experiences of making the move to a care home. These findings indicate a healthcare system that cannot cope with meeting individual acute healthcare needs causing disempowerment and depersonalisation of the older person through system pressures. Moreover, this finding may also identify an ageist attitude towards older people who felt "left out" of the decision-making process, thus minimising the most significant move in that persons' life. Ageism is accepted as an inevitable outcome of growing old, and stereotypical views of older people being dependent and incompetent reinforce healthcare professionals' acceptance and internalisation of negative attitudes towards old age (Swift, Abrams, Lamont, & Drury, 2017). Several research studies have focused on attitudes towards older adults among healthcare providers including Liu, Norman, and While (2015), who identified negative, neutral and positive attitudes towards ageing among nurses' evaluations of older adults. Moreover, it is related that ageism is embedded in the professional culture of nurses in the form of a preference for working with younger patients (Kagan & Melendez-Torres, 2015) and this needs to change. In 2016, the World Health Organization adopted the first global strategy and plan of action on ageing and health. The programme mandates changes in societal attitudes, more accessible environments and changes to healthcare systems that align with the needs of older people.

#### 4.4 | Planning for the future

Although global policy asserts that care provision should enable self-expression and identity, the ability to make choices and to maintain connections with social networks (World Health Organisation, 2015), this study's findings would not support this global directive. Providing care for an ageing population is an ongoing challenge for healthcare systems around the world. This study adds to the body of evidence available which highlights a lack of service provision for older people undertaking this move representing a global political and healthcare failure to address older peoples' social and healthcare needs during the transition process. The implications and recommendations emerging from the findings are important as they may help to inform and enlighten all those involved in the care of older people, families, social workers, community care workers and those in the caring professions. Firstly, while there is recognition that sometimes others have to make decisions about the care



of older people particularly those in crisis (National Institute for Health and Care Excellence (NICE) 2015), the recommendations of Sussman and Dupuis (2014) are significant. Core to the process is planning, decision-making and careful consideration/explanation of the move itself. There is a clear need to involve or include those whose future it is, rather than excluding them to the point where they have little choice or no say.

Considering the implications, recommendations concerning the health and well-being of older people who for whatever reason need to be moved into residential care, include the following:

- Formulate a policy/model of transfer around decision-making, planning and moving to a care home with emphasis on the rights of individuals to autonomy and choice. Strive to involve prospective residents rather than exclude them.
- Develop a clear care home induction process to be instigated remove which should include a visit to proposed care home, moving day plan, welcome orientation to home, planned meeting with residents and staff, information on facilities, services, identified staff member to "ease transition" by facilitating caring conversations and upholding links to the older person's home and family.
- Support and empower older people to plan for the future when deciding on their own long-term care needs.
- Consider involving advocacy services who may positively facilitate the transition to a care home and help to maximise the quality of life and well-being of individuals.
- Future research should include the perspective of healthcare professionals involved in relocation of older people to care homes.
- Best practice policy directives on moving to a care home should include the development of auditable guidelines to include equal access to health and social care services post-transition.

## 5 | LIMITATIONS

This study was conducted in one geographical area in the UK, and the authors acknowledge that this may have a bearing on the findings. Reliance on "gatekeepers" for recruitment was a reality for this study, and it may have been the case that this introduced an element of bias into the sample selection. It could also be argued that the study may have benefitted from interviews with other key stakeholders involved in the transition process (e.g. hospital staff, community care managers, care home staff and families) and this could form the basis of a future study in this field.

## 6 | CONCLUSION

This study offers novel insight from the person's perspective on how they perceive moving into a care home to be at "the mercy" of others: families, social workers, hospital nursing staff, community care managers and care home staff. People who are unwell and vulnerable are

moving, as it were, into the unknown, a new environment, new surroundings, new people, new ways of doing things and a new form of care. In essence, the move to a care home involves complex changes and losses that can affect an individual's well-being and identity.

Hospital nursing staff, community care managers and care home managers play a significant role in influencing the experiences of the individual and the transition experience, when older people first move to the care home. The importance of involving "the person" in making the decision to move and having a choice of care home is vital and has a hugely significant impact on their experience of transition. Perceptions of choice may be one mechanism by which to maintain residents' sense of autonomy and improve overall satisfaction with care received. Moreover, maintaining continuity between the persons past and present roles, and providing opportunities to form new relationships with other residents and staff are also important factors which contribute to the person's adaption process.

We recommend research from the perspective of healthcare professionals involved in the relocation of older people to care homes. Only with rigorous nursing research can we inform policymakers and service providers on how to meet older person's physical, emotional and social needs prior to, during and following relocation to a care home.

### Implications for practice

- There is a need to standardise approaches and develop person-centred interventions to support older people considering relocation to a care home and nurses have a key role to play in making this happen.
- Best practice policy directives on moving to a care home should include the development of auditable guidelines to include equal access to health and social care services post transition.
- Future research should include the perspective of health care professionals involved in supporting older people in making the move to care homes.

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The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

## AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and met all four criteria for authorship of the following criteria (ICMJE [<http://www.icmje.org/recommendations/browse/roles-and-responsibilities/defin>]

ing-the-role-of-authors-and-contributors.html)): substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data. All authors drafted the article or revised it critically for important intellectual content.

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## REFERENCES

- Age UK (2017). *Later life in the United Kingdom*. Retrieved from [https://www.ageuk.org.uk/Documents/EN-GB/Factsheets/Later\\_Life\\_UK\\_factsheet](https://www.ageuk.org.uk/Documents/EN-GB/Factsheets/Later_Life_UK_factsheet)
- Armstrong, C., Hamilton, L., & Shenkin, S. (2014). *Factors predictive of nursing home admission directly from hospital: A systematic review*. Personal communication.
- Backhouse, T., Kenkmann, A., Lane, K., Penhale, B., Poland, F., & Killelt, A. (2016). Older care-home residents as collaborators or advisors in research: A systematic review. *Age and Ageing*, 45(3), 337–345. <https://doi.org/10.1093/ageing/afv201>
- Barnett, K., Mercer, S. W., Norbury, M., Watt, G., Wyke, S., & Guthrie, B. (2012). Epidemiology of multimorbidity and implications for health care, research, and medical education: A cross-sectional study. *The Lancet*, 380(9836), 37–43.
- Bazeley, P. (2013). *Qualitative data analysis: Practical strategies*. London: Sage.
- Bowers, B., Nolet, K., & Jacobson, N. (2015). Sustaining culture change: Experiences in the green house model. *Health Services Research*, 51 (Suppl 1), 398–417.
- Bradshaw, S., Playford, E., & Riaz, A. (2012). Living well in care homes: A systematic review of qualitative studies. *Age and Ageing*, 41(4), 429–440. <https://doi.org/10.1093/ageing/afs069>
- Brandburg, G., Symes, L., Mastel-Smith, B., Hersch, G., & Walsh, T. (2013). Resident strategies for making a life in a nursing home: A qualitative study. *Journal of Advanced Nursing*, 69(4), 862–874. <https://doi.org/10.1111/j.1365-2648.2012.06075.x>
- Brownie, S., Horstmannhof, L., & Garbutt, R. (2014). Factors that impact residents' transition and psychological adjustment to long-term aged care: A systematic literature review. *International Journal of Nursing Studies*, 51(12), 1654–1666. <https://doi.org/10.1016/j.ijnurstu.2014.04.011>
- Cambridge Dictionary (2019). Retrieved from <https://dictionary.cambridge.org/dictionary/english/mercy?q=be+at+the+mercy+of>
- Chao, S. Y., Lan, Y. H., Tso, H. C., Chung, C. M., Neim, Y. M., & Clark, M. J. (2008). Predictors of psychosocial adaptation among elderly residents in long-term care settings. *Journal of Nursing Research*, 16(2), 149–158. <https://doi.org/10.1097/01.JNR.0000387300.22172.c6>
- Cheek, J., Ballantyne, A., Byers, L., & Quan, J. (2007). From retirement village to residential aged care: What older people and their families say. *Health & Social Care in the Community*, 15(1), 8–17.
- Cooney, A. (2012). 'Finding home': A grounded theory on how older people 'find home' in Long-term care settings. *International Journal of Older People Nursing*, 7(3), 188–199.
- Corbin, J., & Strauss, A. (2008). *Basics of qualitative research* (3rd edn.). Thousand Oaks, CA: Sage.
- Davies, S., & Nolan, M. (2006). 'Making it better': Self-perceived roles of family caregivers of older people living in nursing home: A qualitative study. *International Journal of Nursing Studies*, 43, 281–291.
- Dossa, A., Bokhour, B., & Hoenig, H. (2012). Care transitions from the hospital to home for patients with mobility impairments: Patient and family caregiver experiences. *Rehabilitation Nursing*, 37(6), 277–285.
- Ellis, J. M. (2010). Psychological transition into a residential care facility: Older people's experiences. *Journal of Advanced Nursing*, 66, 1159–1168.
- Falk, H., Wijk, H., Persson, L., & Falk, K. (2013). A sense of home in residential care. *Scandinavian Journal of Caring Sciences*, 27(4), 999–1009. <https://doi.org/10.1111/scs.12011>
- Fraher, A., & Coffey, A. (2011). Older people's experiences of relocation to long-term care. *Nursing Older People*, 23(10), 23–27. <https://doi.org/10.7748/nop2011.12.23.10.23.c8838>
- Fuji, K. T., Abbott, A. A., & Norris, J. F. (2012). Exploring care transitions from patient, caregiver, and health-care provider perspectives. *Clinical Nursing Research*, 22(3), 258–274.
- Gilbert, S., Amella, E., Edlund, B., & Nemeth, L. (2015). Making the move: A mixed research integrative review. *Healthcare*, 3(3), 757–774. <https://doi.org/10.3390/healthcare3030757>
- Graneheim, U. H., Johansson, A., & Lindgren, B. (2014). Family caregivers' experiences of relinquishing the care of a person with dementia to a nursing home: Insights from a meta-ethnographic study. *Scandinavian Journal of Caring Sciences*, 28(2), 215–224. <https://doi.org/10.1111/scs.12046>
- Hanratty, B., Holmes, L., Lowson, E., Grande, G., Addington-Hall, J., Payne, S., & Seymour, J. (2012). Older adults' experiences of transitions between care settings at the end of life in England: A qualitative interview study. *Journal of Pain and Symptom Management*, 44(1), 74–83. <https://doi.org/10.1016/j.jpainsymman.2011.08.006>
- Johnson, R., Popejoy, L., & Radina, M. (2010). Older adult's participation in nursing home placement decisions. *Clinical Nursing Research*, 19(4), 358–375. <https://doi.org/10.1177/1054773810372990>
- Kagan, S. H., & Melendez-Torres, G. J. (2015). Ageism in nursing. *Journal of Nursing Management*, 23(5), 644–650. <https://doi.org/10.1111/jonm.12191>
- Keister, K. J. (2004). *Relocation appraisal of nursing home residents (Unpublished Doctoral Dissertation)*. Cleveland, OH: Case Western Reserve University.
- Koppitz, A., Dreizler, J., Altherr, J., Bosshard, G., Naef, R., & Imhof, L. (2017). Relocation experiences with unplanned admission to a nursing home: A qualitative study. *International Psychogeriatrics*, 29(3), 517–527. <https://doi.org/10.1017/S1041610216001964>
- Križaj, T., Warren, A., & Slade, A. (2018). 'Holding on to What I Do': Experiences of older Slovenians moving into a care home. *The Gerontologist*, 58(3), 512–520. <https://doi.org/10.1093/geront/gnw150>
- Kuluski, K., Ho, J. W., Hans, P. K., & Nelson, M. L. A. (2017). Community care for people with complex care needs: bridging the gap between health and social care. *International Journal of Integrated Care*, 17(4), 2. <https://doi.org/10.5334/ijic.2944>
- Lee, V., Simpson, J., & Froggart, K. (2013). A narrative exploration of older peoples transitions in to residential care. *Ageing and Mental Health*, 17(1), 48–56. <https://doi.org/10.1080/13607863.2012.715139>
- Lincoln, Y., & Guba, E. (1985). *Naturalistic enquiry*. Thousand Oaks, CA: Sage Publications.
- Liu, Y. E., Norman, I. J., & While, A. E. (2015). Nurses' attitudes towards older people and working with older patients: An explanatory model. *Journal of Nursing Management*, 23(8), 965–973. <https://doi.org/10.1111/jonm.12242>
- Maregoni, A., Angleman, S., Melis, R., Mangialasche, F., Karp, A., Garmen, A., ... Fratiglioni, L. (2011). Aging with multimorbidity: A systematic review of the literature. *Ageing Research Reviews*, 10(4), 430–439. <https://doi.org/10.1016/j.arr.2011.03.003>
- Marshall, E., & Mackenzie, L. (2008). Adjustment to residential care: The experience of newly admitted residents to hostel accommodation in Australia. *Australian Occupational Therapy Journal*, 55, 123–132.



- McCarthy (2016). What is a care home- McCarthy & Stone. Retrieved from <https://www.mccarthyandstone.co.uk/about-us/what-we-do/what-is-a-care-home/>
- McCormack, B., & McCance, T. (2017). *Person centred practice in nursing & health*. Chichester: Wiley-Blackwell.
- McKenna, D., & Staniforth, B. (2017). Older people moving to residential care in Aotearoa New Zealand: Considerations for social work at practice and policy levels. *Aotearoa New Zealand Social Work*, 29(1), 28–40. <https://doi.org/10.11157/anzswj-vol29iss1id215>
- National Institute for Health and Care Excellence (NICE) (2015). *Transition between inpatient hospital settings and community or care home settings for adults with social care needs (NG27)*. Retrieved from <https://www.nice.org.uk/guidance/ng27/chapter/Recommendations#discharge-from-hospital>
- Nolan, M. R., Hanson, E., Magnusson, L., & Anderson, B. (2003). Gauging quality in constructivist research: The Aldre Vast Sjuharadmodel revisited. *Quality in Ageing*, 4, 22–27.
- NVivo qualitative data analysis Software (2018) QSR International Pty Ltd. Version 12.
- Nwe, W. T., D'Souza, G., & Sheehan, B. (2011). Expectations and experience of moving to a care home: Perceptions of older people with dementia. *Dementia*, 10(1), 7–18.
- Phelan, A., Rohde, D., Casey, M., Fealy, G., Felle, P., Lloyd, H., & O'Kelly, G. (2017) *Patient narrative project for person-centred coordinated care*. Dublin: UCD, IPPOSI & HSE.
- Reed, J., Cook, G., Sullivan, A., & Burrige, C. (2003). Making a move: Care home residents' experiences of relocation. *Ageing & Society*, 23, 225–241. <https://doi.org/10.1017/S0144686X02001101>
- Ryan, A., & McKenna, H. (2015). "It's the little things that count". Families experience of roles, relationships and quality of care in nursing homes. *International Journal of Older People Nursing*, 10, 38–47. <https://doi.org/10.1111/opn.12052>
- Strauss, A., & Corbin, J. (1990) *Basics of qualitative research* (1st edn.). Thousand Oaks, CA: Sage.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: techniques and procedures for developing grounded theory* (2nd edn.). Thousand Oaks, CA: Sage.
- Sury, L., Burns, K., & Brodaty, H. (2013). Moving in: adjustment of people living with dementia going into a nursing home and their families. *International Psychogeriatrics*, 25(6), 867–876. <https://doi.org/10.1017/S1041610213000057>
- Sussman, T., & Dupuis, S. (2012). Supporting a relative's move into long-term care: Starting point shapes family members' experiences. *Canadian Journal on Aging/La Revue Canadienne Du Vieillessement*, 31(04), 395–410. <https://doi.org/10.1017/S0714980812000384>
- Sussman, T., & Dupuis, S. (2014). Supporting residents moving into long-term care: multiple layers shape residents' experiences. *Journal of Gerontological Social Work*, 57(5), 438–459. <https://doi.org/10.1080/01634372.2013.875971>
- Swift, H. J., Abrams, D., Lamont, R. A., & Drury, L. (2017). The risks of ageism model: How ageism and negative attitudes toward age can be a barrier to active aging. *Social Issues and Policy Review*, 11, 195–231. <https://doi.org/10.1111/sipr.12031>
- Thein, N. W., D'Souza, G., & Sheehan, B. (2011). Expectations and experience of moving to a care home: Perceptions of older people with dementia. *Dementia*, 10, 7–18. <https://doi.org/10.1177/1471301210392971>
- Toles, M. P., Abbott, K. M., Hirschman, K. P., & Naylor, M. D. (2012). Transitions in care among older adults receiving long-term services and supports. *Journal of Gerontological Nursing*, 38(11), 40–47.
- Walker, E., & McNamara, B. (2013). Relocating to retirement living: an occupational perspective on successful transitions. *Australian Occupational Therapy Journal*, 60, 445–453.
- Wilson, C. B., & Clissett, P. (2011). Involving older people in research: Practical considerations when using the authenticity criteria in constructivist inquiry. *Journal of Advanced Nursing*, 67(3), 677–686. <https://doi.org/10.1111/j.1365-2648.2010.05500.x>
- World Health Organisation (2015). *World report on ageing and health*. Retrieved from [http://apps.who.int/iris/bitstream/handle/10665/186463/9789240694811\\_eng.pdf?sequence=1](http://apps.who.int/iris/bitstream/handle/10665/186463/9789240694811_eng.pdf?sequence=1)
- World Health Organization (2018a). *Global consultation on integrated care for older people (ICOPE)—the path to universal health coverage: report of consultation meeting 23–25 October 2017 in Berlin, Germany*. Geneva: WHO.
- World Health Organization (2018b). *Global campaign to combat ageism* [online]. Retrieved from <https://www.who.int/ageing/ageism/campaign/en/>
- Zamanzadeh, V., Rahmani, A., Pakpour, V., Chenoweth, L. L., & Mohammadi, E. (2016). Psychosocial changes following transition to an aged care home: Qualitative findings from Iran. *International Journal of Older People Nursing*, 12, 1–10.

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#### **4.8 Interview Two: (Four to six weeks post move)**

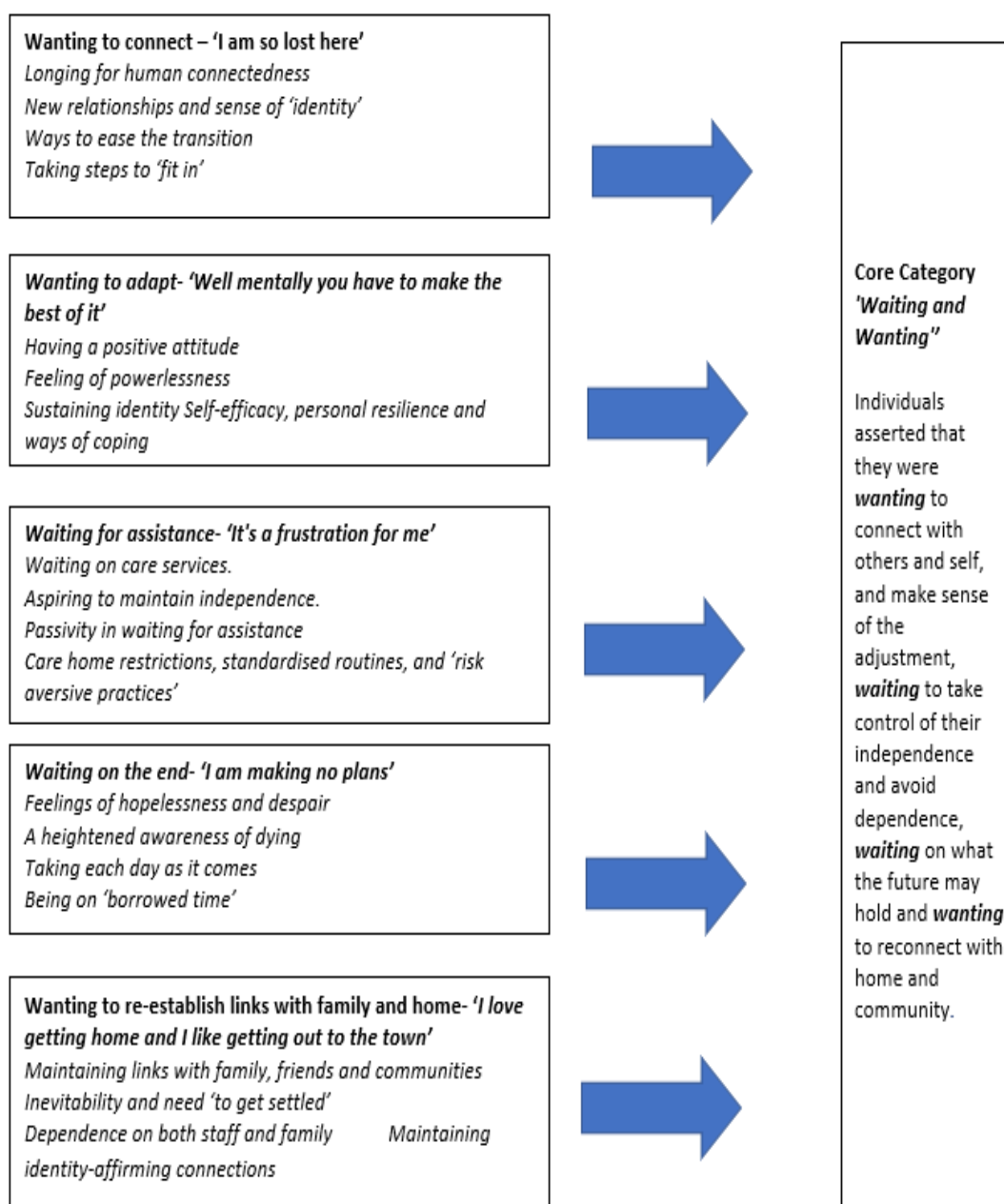
The second interviews were conducted between May 2017 and October 2018. Semi-structured interviews were used to elucidate the early ongoing experiences and perspectives from seventeen individuals who had moved into a care home. The individual interviews were conducted in private rooms in the eight different care homes. The audio taped interviews were transcribed verbatim with each interview lasting approximately 60 minutes. The interview schedule evolved commensurate with category and subcategory dimensions using grounded theory approach.

#### **4.9 Concepts, categories, and core category**

As data collection proceeded and the basis of a theory began to emerge, it became necessary to theoretically sample participants in residential and rural care homes. Interim findings indicated something different about the experiences of older people in care homes in urban areas in terms of their perception of maintaining links with family, friends, and communities. In the final stage of coding, the process of identifying and choosing the core category occurred by systematically connecting it to other categories and validating those similarities and relationships (Strauss and Corbin, 2008). Five distinct categories captured the experience of this early post-move period. These were: 1) Wanting to connect: *'I am so lost here'*, 2) Wanting to adapt: *'Well mentally you have to make the best of it'*, 3) Waiting for assistance: *'it's a frustration for me'*, 4) Waiting on the end: *'I am making no plans'*, and 5) Wanting to re-establish links with family and home: *'I love getting home and I like getting out to the town'*. Together these five categories formed the basis of the core category 'Wanting and Waiting' which captures the perceived early transitional experiences of the men and women in the study. Within this study the initial time of adaptation

following the move to the care home was seen by many individuals as causing a loss of autonomy independence, decision-making, meaningful engagement, and continuity of former roles. See Figure 4.3 which demonstrates the relationship of the major categories to each other and to the core category.

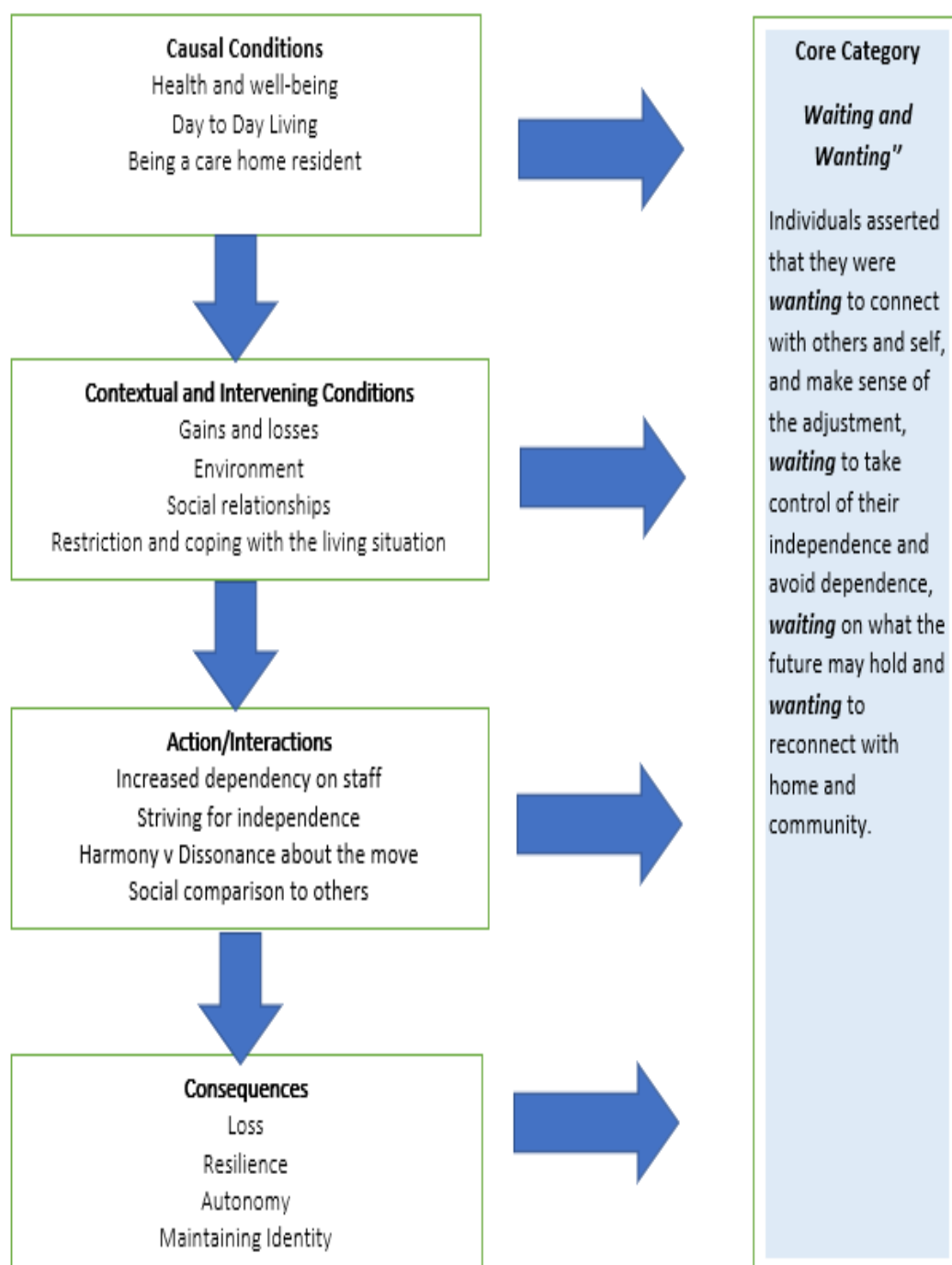
**Figure 4.3:** Relationship of major categories to each other and to the core category



#### **4.10 Paradigm Model Two**

The contextual and causal conditions for individuals at this timepoint relate to the early weeks following the move to a care home. The intervening conditions are interconnected to initial reactions to the move that are marked by emotional responses as evidenced within actions/interactions. These also relate to transitional influences e.g. personal characteristics, values, history, and circumstances of admission. These actions/interactions are the ways in which individuals handle situations, demonstrating the connection to the core category 'Waiting and Wanting'. Within this context, most individuals within this study identified that adapting to life in a care home was an ongoing process that for the main part they were trying to navigate themselves whilst being dependent on care home staff and family. The consequences at this time point were as a result of the actions/interactions leading to a loss of independence, autonomy, decision-making, meaningful engagement, and continuity of former roles. In addition, concepts within the consequences category of the Paradigm model underpin the core category as individuals identified 'Wanting' to reconnect with their family, friends, home and community, and were 'Waiting' to make sense of the process of adaptation, while taking control of their lives, avoiding dependence and waiting on their different needs to be met. The core category connects to emergent categories which encompassed descriptions of individuals' senses of identity, connectedness with others, autonomy, and caring practices. See Figure 4.4 for Paradigm Model Interview Two.

**Figure 4.4: Paradigm Model Two**



#### 4.11 ‘Waiting and Wanting’: older peoples’ initial experiences of adapting to life in a care home: a grounded theory study (Paper Two)

This paper reports key findings pertaining to the experiences of seventeen older people within the four to six weeks post-move period in their respective care home. Data analysis revealed the following five distinct categories: 1) Wanting to connect: *‘I am so lost here’*, 2) Wanting to adapt: *‘Well mentally you have to make the best of it’*, 3) Waiting for assistance: *‘it’s a frustration for me’*, 4) Waiting on the end: *I am making no plans’*, and 5) Wanting to re-establish links with family and home: *‘I love getting home and I like getting out to the town’*. Together these five categories formed the basis of the core category *‘Waiting and Wanting’* which encapsulates the overall experiences of adjusting to life in a care home, for the men and women in this study. Individuals asserted that they were wanting to connect with others and self, and make sense of the adjustment, waiting to take control of their independence and avoid dependence, waiting on what the future may hold and wanting to reconnect with home and community.

**Paper Two:** O'Neill, M., Ryan, A., Tracey, A., and Laird, L. (2020). ‘Waiting and Wanting’: Older peoples’ initial experiences of adapting to life in a care home: A grounded theory study. *Ageing and Society*, 1-25.

<https://doi:10.1017/S0144686X20000872>



# ARTICLE

## ‘Waiting and Wanting’: older peoples’ initial experiences of adapting to life in a care home: a grounded theory study

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### Abstract

A grounded theory approach, consistent with the work of Strauss and Corbin, was used to undertake semi-structured interviews with 17 older people, to explore their experiences of living in a care home, during the four- to six-week period following the move. Purposive sampling was initially adopted, thereafter, theoretical sampling was employed to recruit individuals identified by care managers within older peoples’ community teams and care home managers within a large Health and Social Care Trust in the United Kingdom. Consistent with grounded theory methodology, data collection and analysis occurred simultaneously. Constant comparative analysis underpinned data analysis and data management techniques. Data analysis revealed five distinct categories that captured these experiences. These were: (a) wanting to connect – ‘I am so lost here’, (b) wanting to adapt – ‘Well mentally you have to make the best of it’, (c) waiting for assistance – ‘it’s a frustration for me’, (d) ‘waiting on the end’ – ‘I am making no plans’ and (e) wanting to re-establish links with family and home – ‘I love getting home and I like getting out to the town’. Together these five categories formed the basis of the core category, ‘Waiting and Wanting’, which encapsulates the initial adaptation experiences of the men and women in the study. Findings indicate that individuals were dependent on others to create a sense of belonging, independence and wellbeing. Moreover, risk averse practices were perceived as a threat to individuals’ independence and autonomy. Recommendations include the need to amend policy and practice for the development of a bespoke induction programme for each resident facilitated by a senior member of the care home staff working in partnership with individuals and families, in addition to the health and social care team, to support a more positive transition for new residents, relatives and care home staff.

**Keywords:** older people; adaptation; care home; transitions; grounded theory

### Introduction

Internationally, it is recognised that adapting to life in a care home environment can be an emotional, complex and upsetting occasion for older people as well as

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their families (Ellis, 2010; Brandburg *et al.*, 2013; Sury *et al.*, 2013; Ryan and McKenna, 2015). There is a paucity of research that considers the experiences of individuals in the initial weeks after entry to a care home.

Numerous factors can influence the adaption and adjustment process for older people when relocating to a care home (Bradshaw *et al.*, 2012; Brownie *et al.*, 2014; Križaj *et al.*, 2018; Moore and Ryan, 2017). Some research studies have identified that older people may experience a loss of autonomy, independence and identity, making adaptation to life in a care more challenging. Moreover, older people often struggle to adhere to the routine and rules of the care home environment (Cooney, 2012; Bradshaw *et al.*, 2012; Brandburg *et al.*, 2013; Riedl *et al.*, 2013; Ericson-Lidman *et al.*, 2014). Several research studies convey that care home environments can be restrictive with a lack of privacy, have limited opportunity for social interaction and have regimented practices (Tsai and Tsai 2008; Bradshaw *et al.*, 2012; Cooney 2012; Križaj *et al.*, 2018). Maintaining continuity between the older person's past and present role has been identified as an important factor in the adaptation process after entry to a care home (Bradshaw *et al.*, 2012; Minhat *et al.*, 2013; Brownie *et al.*, 2014; Križaj *et al.*, 2018). There is also evidence to suggest that individuals may experience a greater sense of freedom, be able to regain some of their independence and feel less of a burden to others (Bradshaw *et al.*, 2012; Sullivan and Willis, 2018). Furthermore, research from older people's perspectives suggests that when faced with upsetting situations, older people attempt to preserve goals, values and relationships, and adapt by using cognitive coping mechanisms, as well as employing practical strategies including maintaining social roles and activities, and receiving support from close ongoing relationships (Tanner, 2010; Clarke and Bennett, 2013).

The transition to a care home environment therefore represents a uniquely significant experience for older people. Brandburg (2007) described three identifiable processes associated with the transition to life in a care home: (a) the 'initial reaction' or emotional response to the move which is not dependent on whether the admission is planned or unplanned; (b) 'transitional influences' such as life experience and the meaning attached to the relocation; and (c) 'adjustment', where the individual comes to terms with moving. The second and third stages, transitional influences and adjustment, interact and interplay during the process of transition. As a result, older adults are in a dynamic process of adjusting and readjusting as they interact with various transitional influences such as the formation of new relationships with residents and staff. The end of adjustment occurs when the resident comes to terms with living in a care home, has developed new relationships, maintained old friendships and reflected on their new home environment. According to Brandburg (2007), the final 'acceptance' phase usually occurs between six and 12 months post-admission. This marks the end of the transition period when new residents finally accept living in the nursing home. Contrastingly, Bridges (2004) defined transition as a psychological reorientation with three distinct phases: (a) endings that involve letting go and experiencing loss in some form; (b) a neutral zone that is an in-between phase, usually associated with uncertainty; and (c) the new beginning that may involve a new focus or new identity. Furthermore, the 'transition' process has been defined as occurring as a result of change in a person's life continuing until adaptation occurs, producing fundamental changes to an individual's role or identity (Porter and Ganong, 2005; Wiersma and Dupuis, 2010; Paddock *et al.*, 2019).



Brownie *et al.* (2014) undertook a systematic literature review to identify the factors that impact on residents' transition and psychological adaptation to long-term care facilities. The review was informed by the concept of home, and Bridges' (2004) three stages of transition framework. Bridges' framework provided conceptual models for better understanding of the needs and aspirations of older people who are in the process of this late-life transition. They identified 19 observational, descriptive and cross-sectional studies exploring older peoples' views about their experiences relocating and adjusting to life in a care home. The majority of studies were undertaken within the first two weeks after entry to the home (Iwasiw *et al.*, 1996; Wilson, 1997; Lee, 1999, 2001, 2010; Heliker and Scholler-Jaquish, 2006; Keister, 2006; Komatsu *et al.*, 2007; Walker *et al.*, 2007; Saunders and Heliker, 2008; Johnson *et al.*, 2010; Walker and McNamara, 2013). Two studies were undertaken within the one- to two-month period post-placement (Wilson, 1997; Komatsu *et al.*, 2007) and another study collected data at monthly intervals up to six months after placement (Saunders and Heliker, 2008). Positive adaptation was reported to be influenced by older people being able to retain personal possessions, continue valued social relationships and establish new relationships within the care facility. A qualitative metasynthesis undertaken by Sullivan and Williams (2017) reviewed eight studies of older adults' transition experiences to long-term care facilities, guided by Meleis's (2010) Theory of Transition. Three themes were identified: loss requiring mourning, stability sought by gaining autonomy and acceptance when inner balance is achieved. A more recent systematic review undertaken by Fitzpatrick and Tzouvara (2019) sought to understand what factors facilitate and inhibit the transition for older people who have relocated to a long-term care facility informed by Meleis's Theory of Transition. Data synthesis of 34 studies using a variety of terms, timelines and study designs identified that transition featured potential personal and community-focused facilitators and inhibitors which were mapped to four themes: resilience of the older person, interpersonal connections and relationships, this is my new home and the care facility as an organisation.

Adaptation to care home life is a process that occurs over a period. Part of understanding this process requires recognition of variances in the responses of older adults. Care home residents are often marginalised and excluded from research (Backhouse *et al.*, 2016). Moreover, there is a paucity of research that takes into consideration the relocation process, incorporating residents' experiences with the move (Sussman and Dupuis, 2012).

This paper is part of an overarching research study which aims to increase our understanding of how older adults make the transition from living at home to a care home over the course of 12 months, at four discrete time-points: prior to or within three days of admission and at three time-points after the move (four to six weeks, four to five months and 12 months). The findings from the first time-point indicate that older people making the move to a care home are 'at the mercy' of families, health and social care practitioners, and care home staff (O'Neill *et al.*, 2020).

The main limitation of the current body of literature is the dearth of studies on the experiences of the older person in the initial weeks following the move to a care home. The purpose of gathering data at this critical time-point is to elucidate the

ways in which older people cope with the many changes associated with the move to a care home, *e.g.* leaving home and being separated from family, friends and communities. This initial post-placement time period often follows a time of crisis, an acute illness or a period of hospitalisation (Wilson, 1997; O'Neill *et al.*, 2020). The way in which individuals are supported (or not) during this time period may have a bearing on their adaptation to life in the care home further down the line. This paper therefore focuses on the four- to six-week period after the move. The knowledge gained from this study has the potential to inform care delivery and policy in determining the initial and ongoing support needs of individuals during this critical time period.

### Care home

In this research study, the term 'care home' is used to encompass both residential and nursing homes. A residential care home provides residential accommodation with both board and personal care for persons by reason of old age and infirmity, disablement, past or present dependence on alcohol or drugs, or past or present mental disorder. They do not provide nursing care. A nursing home is any premises used or intended to be used for the reception of and the provision of nursing for persons suffering from any illness or infirmity. Some homes are registered to care for both people in need of residential and nursing care (Regulation and Quality Improvement Authority, 2020).

## Methodology

### Aim

Consistent with grounded theory methodology, the researcher did not identify specific objectives for the study but rather began data collection with a broad aim. To this end, the overall aim of this study was to explore individuals' experiences of moving into a care home with a specific focus on the four to six weeks post-placement period of adjustment.

### Study design

A grounded theory approach, consistent with the work of Strauss and Corbin (1990, 1998), was chosen as it facilitated the development of a new perspective on the experiences of older people in the early weeks after moving to a care home. Grounded theory is recommended when investigating social problems or situations to which people must adapt (Corbin and Strauss, 2008; Morse *et al.*, 2009; Maz, 2013). Grounded theory is an ideal methodology to understand actions and processes through transitions (Morse, 2009), and has been used by qualitative researchers to study processes engaged in by service users (Grant *et al.*, 2009) and family care-givers (Bull and McShane, 2008; Holtslander and Duggleby, 2009; Munhall, 2012). A semi-structured interview schedule was designed to stimulate discussion of individuals' perceptions, thoughts and feelings about their early experiences of living a care home.

### Participants and recruitment

Purposive sampling was used in the initial stages of recruitment and data collection. Thereafter, and consistent with grounded theory methodology, theoretical sampling was employed to recruit a sample of 17 individuals identified by care managers within older peoples' community teams and by waiting lists held by care home managers within a large Health and Social Care Trust in the United Kingdom. The Trust provides health and social care services to a population of approximately 300,000 people. All nursing (N = 21) and residential homes (N = 4) caring for older people within the study site were registered with the regulatory body and the sample was drawn from this list. The care homes (N = 8) selected were located within both rural and urban areas. Community care managers and care home managers had identified potential individuals who met the study's inclusion criteria in that participants were aware that the move was permanent and they achieved a score of 24 or above on the Mini-Mental State Examination (Folstein *et al.*, 1975). The researcher (MON) obtained written consent and individual face-to-face interviews were arranged at a time and place convenient for each participant. Only one older person invited to do so refused to participate in the study.

### Ethics

Ethical approval for the study was obtained through the Ethics Filter Committee of Ulster University, the Office for Research Ethics Committees Northern Ireland, and the Clinical and Social Care Governance Committee of the Health Care Trust. The Code of Ethics of the International Council of Nurses (2006) has underpinned all aspects of ethical considerations for this study which relate to the protection of vulnerable adults, participants' information, consent, autonomy and confidentiality. A distress protocol was developed, and a system of referral and escalation put into place taking due cognisance of the Protection of Vulnerable Adults guidelines (Department of Health, Social Services and Public Safety, 2006), for implementation should any participant become distressed during interview. The interviews were conducted by the first author who is an experienced mental health nurse and can identify early signs of distress. In addition, participants were asked if there was someone she or he would like to have present during the interview, or who could be a contact person in a case of distress. In the event, no participant became distressed. Some gave emotional responses during the interviews. In adherence to the protocol, the interviewer and participant talked about this, and in each case, the participant wanted the interview to proceed, and indeed felt that talking about their experiences was supportive. The care home manager was informed after the interview if the participant had become upset during the interview. The interviewer did not leave the participant until he or she was content. Informed consent was provided by each participant who agreed to take part in the study with an additional clause giving consent to use a digital recorder for the interviews. Assurances of confidentiality and anonymity were provided and supported by the allocation of pseudonyms in the presentation of the study and its findings.

### **Data collection**

Individual face-to-face interviews were arranged at a time convenient for each participant. All interviews were conducted between May 2017 and October 2018. Semi-structured interviews were used to generate discussion that would illuminate ongoing experiences and perspectives from 17 individuals who had moved into a care home. The individual interviews were conducted in private rooms in the eight different care homes. The audio-taped interviews were transcribed verbatim with each interview lasting approximately 60 minutes. Consistent with a grounded theory approach, the semi-structured interviews provided both focus and flexibility (Corbin and Strauss, 2008). Simultaneous data collection and constant comparative analysis were repeated until data saturation was accomplished along with the advancement of theoretical concepts and the development of a core category. As data collection proceeded and the basis of a theory began to emerge, it became necessary to theoretically sample older people in residential and rural care homes as interim findings indicated something diverse about the experiences of older people in care homes within the urban environment. Strauss and Corbin (1998: 201) have described theoretical sampling as a means to 'maximise opportunities to discover variations among concepts and to densify categories in terms of their properties and dimensions'. Therefore, potential participants moving to these types of care homes were invited to take part in the study. The process of theoretical sampling continued until the emerging concepts and categories reached saturation.

The interview schedule evolved commensurate with category and sub-category dimensions using the grounded theory approach. Prompts were used to generate discussion and included:

- Tell me about how you are getting on since you moved into the care home?
- Tell me about how you keep in contact with your family and friends at home?
- How has your life changed since living in this care home?
- Can you tell me about any concerns and/or worries you may have about living here now?
- Prompts on physical, psychological and social wellbeing since admission.

### **Data analysis**

The interviews were recorded and checked to ensure the rigour of the data collection procedures. NVivo 12 qualitative data analysis program software (QSR International, 2018) facilitated the organisation, management and retrieval of transcribed interviews and field notes, and provided tools for coding, categorising and linking qualitative data. Constant comparative analysis underpinned data analysis and data management techniques. Repeated ideas, concepts or elements became apparent, and were tagged with codes extracted from the data. Grouping of codes into concepts and then into categories was undertaken after more data collection and review. As analysis progressed, coding moved towards being 'selective', focusing on those codes which related to emergent main categories. In the final stage of coding, the process of identifying and choosing the core category occurred by systematically connecting it to other categories and validating those similarities



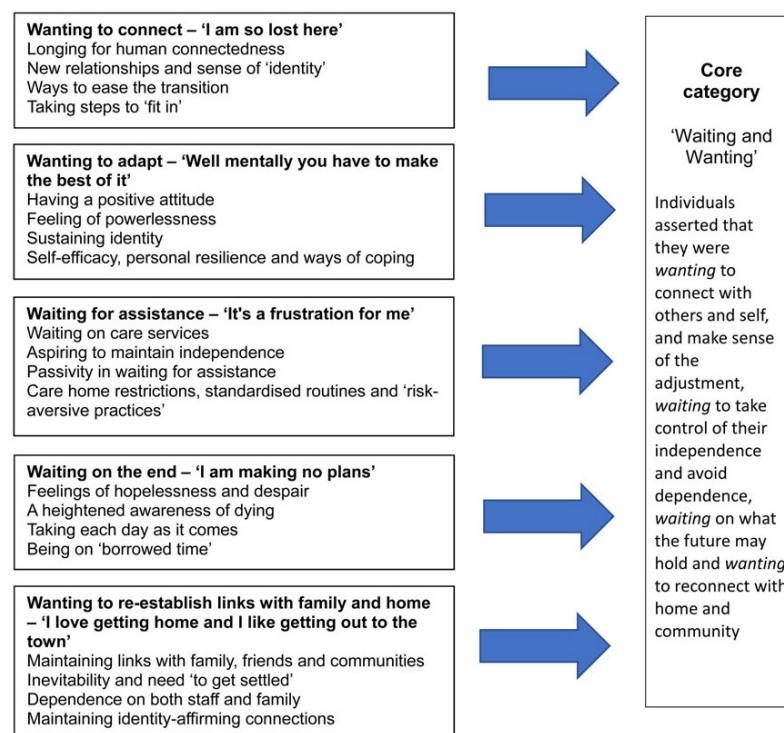


Figure 1. Diagram illustrating relationship of major categories to each other and to the core category.

and relationships (Strauss and Corbin, 1998). The concept of 'Waiting and Wanting' emerged from the final analysis (see Figure 1).

### Ensuring rigour

Numerous strategies were employed to ensure the rigour of the study. The study was conducted with an awareness and application of the underlying principles of the authenticity criteria developed by Nolan *et al.* (2003) and further developed in care homes research by Wilson and Clissett (2011). In the grounded theory approach, validity depends on theoretical sensitivity, which refers to the ability to give meaning to data and the capacity to understand the sources of theoretical sensitivity (Strauss and Corbin, 1990, 1998). The initial interviews were recorded and checked to ensure the rigour of the data collection procedures. The constant comparative analysis of emerging data facilitated the verification of findings and minimised the likelihood of personal bias. The process of theoretical sampling continued until the emerging concepts and categories reached saturation. During the open and axial coding stages, two members of the research team (MON and AT) independently viewed the original uncoded manuscripts and confirmed themes, thus ensuring that interpretations represented the experiences of the individuals.

After the selective coding process, trustworthiness of the data was enhanced by all the research team who reviewed themes and discussed alternative interpretations of the data to maximise credibility, dependability and confirmability (Lincoln and Guba, 1985). In keeping with one of the tenets of grounded theory (Corbin and Strauss, 2008), individuals' own language at all levels of coding was used to further ground theory construction and add to the credibility of findings.

## Findings

### *Profile of individuals*

The 17 individuals who participated in this study comprised ten women and seven men with an average age of 83.3 years. Seven of the individuals were transferred from hospital to the care home and the others were relocated directly from their home. The majority of the individuals (N = 13) were living alone at the time of admission while the minority (N = 4) lived with spouse/family members.

The main reasons cited for prompting the relocation to a care home was deterioration in physical health (N = 11), recent bereavement (N = 3) and no-one to take care of me/changing family circumstances (N = 3). Only four of the 17 participants stated that they had made the decision to move to a care home, and of these four, only two were able to move to the care home of their choice. Demographic details of individuals and reason for admission are outlined in Table 1.

### *From concepts to categories*

This paper reports key findings pertaining to the experiences of 17 older people within the four- to six-week post-placement period in a care home. Data analysis revealed the following five distinct categories: (a) wanting to connect – 'I am so lost here', (b) wanting to adapt – 'Well mentally you have to make the best of it', (c) waiting for assistance – 'it's a frustration for me', (d) 'waiting on the end' – I am making no plans' and (e) wanting to re-establish links with family and home – 'I love getting home and I like getting out to the town'. Together these five categories formed the basis of the core category 'Waiting and Wanting' which encapsulates the overall experiences of adjusting to life in a care home, for the men and women in this study. Individuals asserted that they were wanting to connect with others and self, and make sense of the adjustment, waiting to take control of their independence and avoid dependence, waiting on what the future may hold and wanting to reconnect with home and community. Figure 1 shows the relationship of major categories to each other and to the core category.

### *Wanting to connect – 'I am so lost here'*

Undeniably moving to a care home where the future might appear uncertain is regarded as one of the most daunting and difficult challenges an individual can face in their later life. Some individuals were experiencing a longing for human connectedness in their new environment:

Table 1. Characteristics of the interviewees and details of admission

Pseudonym	Age	Living arrangement prior to move	Individual's account of details surrounding admission to care home	How was admission arranged?
Jane	84	Lived alone in rented accommodation	'Too old to be on my own and I'm frightened of falling.' Jane developed a chest infection, was admitted to hospital and then had poor mobility	Family arranged admission through GP/social worker. Did not visit care home prior to admission
Ellen	82	Lived alone in rented accommodation	Husband died recently, wanted to move to sheltered housing. Nursing home was only available choice	Social worker arranged admission. Ellen wanted sheltered accommodation, but care home was offered as only accommodation available. Did not see care home prior to admission
David	88	Lived alone in family home	Chose care home as wife already there a year previously. Health deteriorated after a fall at home, 'I'm too old to be on my own'	Chose care home for his wife in the first instance then when his health deteriorated he planned the move
Bernadette	92	Lived alone in family home	Had fall at home, admitted to hospital. 'Family thought it was not right for me being on own. Mobility poor - "Doctor says move in"	Daughters visited the home and recommended it to Rita. GP and social worker decided. Rita did not visit home prior to admission
Andrew	82	Lived alone in family home	Wife died, had recent stroke, was taken to hospital. Family overseas	Daughter came home and visited local care homes. Andrew in hospital prior to admission but did not visit care home
Martha	80	Lived alone at home	'Fell at home, needed a new hip.' Changing family circumstances - no-one now at home	Social worker arranged admission. Only care home available. Did not visit care home prior to admission
Sean	60	Lived with wife and children in family home	Developed sepsis, progressed to paraplegia with lesion on spine. Total nursing care required. Facilities at home do not support nursing care	Was transferred straight from hospital to care home which was only one available to meet care needs. Did not visit care home prior to admission.
Tracey	88	Lived alone in rented accommodation	Getting worried about deterioration in health or falling, chose residential care admission	Arranged through social worker who took Rose to see a few care homes and she chose the one she liked the most

(Continued)



Table 1. (Continued.)

Pseudonym	Age	Living arrangement prior to move	Individuals account of details surrounding admission to care home	How was admission arranged?
Molly	80	Lived alone in rented accommodation	'Developed anxiety'. GP advised admission, 'feeling safe now'	Was being placed by social worker in a care home a few miles away from her family. Molly waited on a vacancy becoming available locally. Did not visit care home prior to admission
Charles	83	Lived with wife in rented accommodation	Wife died suddenly who was carer. Had been in a wheelchair for many years due to war injury. Admitted to care home on day of wife's death in a taxi	Charles was admitted to the care home the night his wife died as she was his carer. It was an emergency admission and he had no say in the move nor did he visit the care home prior to admission
Anne	90	Lived alone in own home	Admitted to hospital with transient ischaemic attack, then transferred to nursing home. 'I had no choice'	Was moved to a nursing home initially post-hospital. Anne asked social worker for a transfer to residential care. Did not visit the care home prior to admission
Isobel	96	Lived alone in rented accommodation	Chest infection, admitted to hospital. Reduced mobility in hospital. Son working away	Isobel stated she would have needed carers at home so social worker asked where she would like to go. Requested care home next to home but no vacancies. Did not visit care home prior to admission
Therese	78	Lived at home with brother and sister	Recent stroke. Sister and brother were 'too old to care for me at home'	Therese chose nursing home as she had spent two weeks convalescing post-surgery three years previously. Did not visit home prior to admission day
Tony	87	Lived alone in family home	Developed pneumonia and was admitted to hospital. GP advised admission to care home	GP and social worker arranged admission. Tony knew of care home because it was local but did not visit the care home prior to admission
Hugh	83	Lived alone in family home	Accident at home, admitted to hospital. Reduced mobility. Niece lives far away	Hugh stated pressure 'to release hospital bed' so his niece visited a few care homes and made arrangements for admission which is 30 miles from Hugh's home. Did not visit care home prior to admission



Mona	81	Lived at home with daughter	Poor mobility for many years. Daughter (carer) fell and injured back requiring hospital admission	Mona was admitted to the care home the day her daughter fell and sustained fractures requiring prolonged hospital admission. Her daughter was her carer. It was an emergency admission and she had no say in the move nor did she visit the care home prior to admission
Kevin	83	Lived alone in family home	Fell while shopping, taken to hospital	Hospital staff advised residential care home admission arranged by social workers. Did not visit care home prior to admission

Note: GP: general practitioner.

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I have been doing nothing here, I just sit here and wait for people to come and visit me. (Mona)

Others felt out of place, citing other resident's cognitive impairment and frailty as a fundamental obstacle to social engagement:

I am so lost here, it's not me, it's not home and it's so big, I don't really know where I am at now. It is very hard to find your way. Some of them, but not all of them are beyond making friends, they are not sick, they're old, so they're not good anymore, you have to take your pick. (Ellen)

For some individuals the importance of forming new relationships was seen as being crucial to one's sense of 'identity' and 'connectedness' to people within their new home:

I am just friendly with everyone. I like being friends with people and that is very important to me as I am coming in here as an outsider. (Tracey)

I know I didn't expect to settle quickly, but it's taking a bit longer than I thought it would. I was a bit disappointed when I came because I didn't know any people and I thought that I would. But I've got to know some people now, but I still want to go home. (David)

It was apparent that for some individuals their 'sense of self' was enhanced or reduced through their interaction with and observations of other residents and their reactions to others' behaviour:

It's not home. Everybody says the same, it's great and all that but it's not your own. There's an old lady I met since I came in, she likes me and every morning I must get up and wave to her in the dining room. I suppose when you look at it there are people far worse off than me. Some of them can't even hold the cup up in their hands. (Bernadette)

I'm not really settled here. You see there is no-one here that I could honestly feel that I could be friends with ... so that's it. (Charles)

It was evident that care home staff were primarily perceived as providers of health care delivery only and not as people with whom to develop relationships:

Well they only come in to do tasks and go out again. You don't develop a relationship with them. (Sean)

Some individuals wanted to 'ease the transition' to living in the care home by spending parts of the day outside the home with family:

I suppose I will have to get settled here I have no choice. My sister comes and takes me out for a while every day so thank god for that. I have to get out of here even just for a while. I know that I have to get used to it in here, but it would be too long for me if I had to spend the whole day in here every day. (Molly)

It is evident that maintaining one's identity and autonomy are considered significant factors in an older person's experience of moving into a care home. Some participants were taking steps to 'fit in' and 'feel their way' within this new environment:

I suppose you just have to get on with people, well if you don't it is bad, but thank god I do. I don't go down and sit all day in the big room looking at TV. That's not my thing. And maybe they think I should, but I go down every so often so that they don't think that I'm not mixing. But when I go down there's only two or three of them there sound asleep, so I come back up again. And the others must do the same. (Anne)

***Wanting to adapt – 'Well mentally you have to make the best of it'***

Having a positive attitude towards care home admission can be supported by hospital staff who discussed with one participant, Gerard, the necessity for the move. They provided him with information about the home and discussed the practicalities of the move, thus making it easier for him to become accustomed to a new way of living in the future:

Oh, I love it here I really do. I was told by the staff in the hospital that when you go over to [care home] you will love it. They are a sort of family here you know. Everybody speaks to each other and they are all good to each other. I do tell them that too you know. (Gerard)

There was a sense of individuals making the new home meaningful by bringing in possessions and photographs to symbolise their identity. Continued identification with such meaningful symbols helped to sustain identity:

I suppose I am starting to get used to it now a bit. I am trying anyhow. It is very different you know from being at home with your own people. I have brought some photos here now as well and my bed throws, I like them. I would have liked to bring more but you really don't have much room you know. (Isobel)

Individuals expressed their own sense of self-efficacy, personal resilience and ways of coping with adjusting to life in the care home, by taking 'one day at a time' and mentally 'making the best of it':

Well I always take it one day at a time and thank god it's been good so far. It's the best way to take it, you know, because I wouldn't be doing as well as I'm doing otherwise, you see, I would miss things from home. Well I do a lot of thinking but sure that's no harm. (Anne)

You have to try and accept being here you know but it is very hard, really hard ... it's psychological, but you feel like you are at the end of the road, you know. Well mentally you have to make the best of it that's the main thing. Firstly, settle into the illness, clear your head and your mind and you will get by, otherwise, you would just be depressed. (Andrew)

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A strong part of facing reality for some individuals involved resisting having decisions taken away from them, proposing to fight for their independence and sense of identity:

My life has to change. I cannot leave everything to the doctors. I have to get myself better then I will think differently. I am not thinking properly now, I'm not right yet, I feel scared of everything. I'm not there yet, I have to say to myself that I can still have a life. (Ellen)

Some Individuals were moving towards acceptance of being in a care home, often accompanied by tears as the reality dawned on them that they would not be returning to their home:

Well, you know, I hope I will settle. Some nights I would sit down and have a wee cry to myself. I know now that I have to stay in here because I can't stay on my own. I'm reconciled to that now ... I have to be. (Bernadette)

Others were putting on a brave face for the care home staff and their family:

It's easier to smile than cry. You've a lot to answer for after you've cried, you know, was that necessary ... well I have to put on a brave face for my wife and the people here. You see my wife she has been through so much in the past year and she has never failed me. I would fail her if I broke down ... and the staff well you see they expect you just to get on with it, pull yourself together like. (Sean)

Other individuals were self-assured in the decision they had made to move to a care home. Reflecting on the positive elements of the relocation, opportunities were identified to form new relationships, gain staff support with aspects of care, and pursue former hobbies and activities:

Life is sort of different now. I am content now; I will not be going anywhere else ... They let you do what you want and don't force you to do anything, I like that ... you see that's me ... Moving here is the right decision for me. I know now that I had to leave the house. At the end of the day it is only bricks and mortar. (Gerard)

Yeah, it's good to get someone to do something for you. It takes the pressure off me. I feel safe here. I like going out for a walk ... you know I am just happy with the little things. (Tracey)

However, some individuals considered their self-determination at risk because they felt restricted by care home routines and practices which was experienced as a feeling of powerlessness:

I do think that there are too many rules when you are living here. It is a big change for me to live away from my home and my life. I am not sure if it is a good change ... I suppose time will tell. (Andrew)

***Waiting for assistance – ‘It’s a frustration for me’***

Individuals talked about how having to wait on care services had a negative effect on their individuality and independence, and curtailed them from making the progress they would have liked:

The stroke nurse who was to do the swallowing test never came. She was to sign me off for swallowing so that I could eat bread ... You see I am very determined to be as independent as I can be? I would love to be able to walk to the toilet on my own. I would just like more progress. Every time I get a chance to walk and work at my arm, I take it, I do all the physio exercises that I am told. (Therese)

I am lost without my glasses because reading is very important to me so without them ... well what else can you do? I read all my life and I miss that. I hope that they get here soon. The fella tested my eyes weeks ago, but I haven’t heard a word about it since. I’m just wondering what’s happening and that they have been ordered because I need them. (Tracey)

Aspiring to maintain independent physical function was important to some individuals who were happy with improvements in their health following physiotherapy and self-governed exercise routines, while others were frustrated about losing progress made while in hospital, making them more dependent on staff for assistance:

They got me walking in hospital, but they don’t do that here. I have never been up walking and they don’t give you physio ... and it’s awful when they let you go on ringing that bell and just ignore you, and you have been waiting for over an hour and nothing happens. I have had to phone my family to tell them to phone the home and ask them to answer the bell! (Andrew)

I’ve just been plodding along day to day, it’s the same day well every day really, I feel trapped. I have to depend on so many people. Just even to get out of bed. My wife does my physio when she comes in, especially my legs. (Sean)

Care home restrictions, standardised routines and ‘risk-averse practices’ threatened individuals’ independence and autonomy, and generated frustration and passivity in waiting for assistance:

I like to do as much ... well as much as I can for myself. But they don’t like it, for me to be independent. The staff will treat you well, but some of them are like the Gestapo ... kind of serious, they don’t ask you nicely to do something. They sort of demand you do things because we have to sort of answer to their call you know, so you don’t want to give them too much reason to be annoyed with you, I don’t anyway. (Charles)

It’s a frustration for me having to wait on the staff and ringing that bell. Some of the nurses are nice. But if you need help, they aren’t in a hurry. I am getting to know who to ask now. (Ellen)

Although I have a Zimmer frame, I still have to have someone to take me to the toilet, I’m not allowed to walk on my own, but I think I’m fit to walk on my own. I feel restricted I think that’s my main problem. (David)



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***Waiting on the end – 'I am making no plans'***

Some individuals expressed feelings of hopelessness and despair about the future, seeing no purpose when their physical, mental and social abilities were diminished:

I am getting to the stage that I don't want to go on. I can't go on like this, I am in a lot of pain. (Mona)

For others these feelings varied; one participant recognised how on admission she wished for death. This was a personal reflection of psychological wellbeing at that time:

I was so down when I first came here. The nurse when she came last week, she said I had changed, that I was getting better ... Well less depressed. I know that at first, I was bad, I was trying to write a suicide note, I was scared. (Ellen)

Death was an inevitable part of life for many individuals who often said they were taking each day as it comes and not worrying too much about tomorrow:

I don't know what is going to happen in the future. I always thought that I wouldn't like to die a sudden death. I would like to be ready for death. But other than that, I don't think too far ahead. (Bernadette)

I am making no plans. If I am here tomorrow, then I am here tomorrow and that's it. I have had a good life. Every day I go to bed I say to myself I wonder will you be here in the morning. (Tony)

Accordingly, for some individuals, death and dying framed their present outlook on life. Some spoke about 'of being on borrowed time', 'feeling ready to die' and some even welcomed it:

I don't see much of a future I don't have anything to look forward to ... I look forward to when I would die. I don't think I will last that long; I don't know. Well I have a chest problem and a blood problem. I am happy to go whatever happens. (Charles)

My life is different here. I don't see ... well at my age now, I don't see much future except death. I wasn't very well this last while ... I was telling them I was going to die. (Jane)

As individuals observed contemporaries' deaths, a heightened awareness of dying became evident:

The staff here keep it very quiet if someone is ill. I've noticed that when you're waiting for someone to die, there's hints, for example there's the trolley arriving, when you see that you know that someone is seriously ill ... But you are disappointed if there's a death here. There was one last week, everyone feels it. There's another lady ill now, it puts us off, and we're not in the same good humour. (David)

For some, experiencing a loss of family created an awareness of their own mortality:

My sister died recently, it was a big loss to me you know but what can you do, if god wants them, he takes them. That's the way ... sure, our own day will come. (Isobel)

***Wanting to re-establish links with family and home – 'I love getting home and I like getting out to the town'***

Maintaining links with family, friends and communities was important to reinforce a sense of self and to safeguard against a threatened identity or wellbeing:

I have a cousin who comes in ... Emily, she comes in. She lives close by, so it is nice to see her. My niece used to come down every day at the beginning, but I hardly see her now. (Mona)

I suppose at my age there isn't much to look forward too, but I look forward to seeing my family coming in. I haven't been out since I came here, it would be nice just to go home for a while to see them and have my dinner. (Isobel)

There was recognition of the inevitability and need 'to get settled' in the care home on a gradual basis, while maintaining links with family which was also identified:

I suppose what will help me settle is...well I like to be independent and do my own thing you know...so I hope that I will be able to keep doing that here as I need to keep getting out and about and doing the things that I want. You see I like meeting people, I always have done and going out with my sisters. (Molly)

Individuals experienced a dependence on both staff and family to get out or come into the care home to 'see family', 'see my home', 'go to the chapel', 'go shopping' or just 'be in the garden':

I haven't been out since I've been here. It's such a bother, I think we will have to wait to the summer to someone brings us out. The staff said it's too cold to go out now ... But my niece comes to see me every week and then I have other visitors come too. (Martha)

I would really like to go to the chapel, but I can't go on my own. Well not at present with my foot ... but I could go out in a wheelchair if someone would take me. I don't think there is anybody that would do that here. (Isobel)

I haven't been out home since I came here. They probably think that it would upset me too much ... I like my family coming to visit. I would like to get outside to be in the fresh air and to get out for a run home to see the house and the neighbours. (Andrew)

Most individuals expressed the view that they wanted to maintain social contacts outside the care home to maintain identity-affirming connections and be part of the community:

I love getting home and I like getting out to the town you know. I just like to see if there is any building going on or what's happening in the town. (Tracey)

A lot of people come at the beginning to see you when you move into the home, but it tails off after that. My nephew took me out to tea that was good. I like getting out, it is a nice change. My other niece will be back to see me this coming week. (Therese)

## Discussion

As there is limited research that incorporates residents' experiences during the initial weeks following entry to a care home (Lee *et al.*, 2002; Fraher and Coffey, 2011; Johnson and Bibbo, 2014; Sussman and Dupuis, 2014), this study set out to explore older peoples' experiences of the first four to six weeks following the move. Five distinct categories captured the experience of the four- to six-week post-placement period. These were: (a) wanting to connect – 'I am so lost here', (b) wanting to adapt – 'Well mentally you have to make the best of it', (c) waiting for assistance – 'it's a frustration for me', (d) 'waiting on the end' – 'I am making no plans' and (e) wanting to re-establish links with family and home – 'I love getting home and I like getting out to the town'. Together these five categories formed the basis of the core category 'Waiting and Wanting' which encapsulates the perceived transitional experiences of the men and women in the study. The core category of 'Waiting and Wanting' provides descriptions of individuals' experiences of 'wanting' to reconnect with their family, friends, home and community, and 'waiting' to make sense of the process of adaptation, while taking control of their lives and avoiding dependence. The core category connects to emergent categories which encompassed descriptions of individuals' senses of identity, connectedness with others, autonomy and caring practices.

Within this study the period of adaptation following the move to the care home was viewed by many individuals as leading to a loss of independence, autonomy, decision-making, meaningful engagement and continuity of former roles. Moreover, the loss of an individual's home life presented a major challenge threatening identity, belonging and sense of self (Lee *et al.*, 2013; Brownie *et al.*, 2014; Paddock *et al.*, 2019), and for many a sense of belonging was taking time to develop (Lindley and Wallace, 2015). Individuals were clearly 'wanting' to connect with others in this new environment, and at the same time 'wanting' to re-establish links with family and home. Numerous studies have found that leaving home and being separated from family and communities compounds these losses and feelings of isolation (Iwasiw *et al.*, 1996; Lee, 1999; Bland, 2005; Heliker and Scholler-Jaquis, 2006; Saunders and Heliker, 2008; Fraher and Coffey, 2011; Hutchinson *et al.*, 2011). Adapting to a care home's 'rules and regulations' and being subjected to 'waiting' for assistance were sources of frustration. The need to 'learn the ropes' is an additional source of stress and anxiety for some individuals (Wilson, 1997; Lee, 2001; Heliker and Scholler-Jaquis, 2006).

Many anxieties, including health and social issues, can affect the adaption and adjustment process for older people after moving to a care home (Bradshaw *et al.*, 2012; Brownie *et al.*, 2014; Križaj *et al.*, 2018). Within this study, some



individuals experienced emotional responses in their early weeks of living in the care home, reporting 'It's hard to find your way', 'I am so lost here'. These experiences have been previously identified by Bridges (2004) when considering the early transition stages of moving to a care home, *i.e.* an ending; and a period of confusion which can lead to high anxiety levels; and a new beginning. Within this study, individuals whose relocation experience was deemed to be positive, expressed hopeful affirmations 'Life is sort of different now. I am content now', 'Oh, I love it here I really do'. It has been recognised within Brandburg's (2007) transition process framework how an initial reaction to the move can be marked by emotional responses, and how personal characteristics, values, the history and admission circumstances can influence transitional experiences thereafter. The findings of this study resonate with the first two stages of Brandburg's (2007) transition process framework in that the first stage identifies an initial reaction to the move that is marked by emotional responses; and the second stage as transitional influences, *e.g.* personal characteristics, values, history and circumstances of admission. Within this context, most individuals within this study identified that adapting to life in a care home was an ongoing process that for the main part they were trying to navigate themselves with little support from care home staff or others. This was perceived by individuals as an upsetting and worrying experience during the four- to six-week adaptation phase of settling into life in a care home.

Meleis's theory of transitions explains how a person relates to their environment and health. A change in health and environment can change how a person perceives his or her role. Furthermore, an individual's response to change can be influenced by internal (attitude, knowledge, cultural beliefs) and external factors (social support, socio-economic status) (Meleis, 2010). Within this study, some individuals spoke about their frustration of 'waiting for assistance' from care staff to attend to personal needs and the importance of maintaining their own independence and 'identity'. They expressed annoyance and resentment that staff were preventing them from doing the things they wanted to do or were taking their independence away by doing things for them that they were able to manage themselves. Such staff behaviour was construed as restrictive and limiting autonomy. These experiences are also echoed in the findings of Paddock *et al.* (2019), who suggested that institutional restrictions, standardised routines and strict risk management policies can threaten individuals' independence and autonomy. It has been recognised that when independence is removed from a person's life, an individual can feel defeated, depressed or begin to doubt their own ability to care for themselves (Wiersma and Dupuis, 2010; Custers *et al.*, 2012). Moreover, low expectations can lead to reduced capabilities and can be self-fulfilling, causing deterioration in health and cognitive ability (Chin and Quine, 2012; Lee *et al.*, 2013; Zamanzadeh *et al.*, 2016) and in the worst case scenario, the loss of independence can lead to the loss of a will to live: 'I would rather die than live in a care home' (Österlind *et al.*, 2017). For all the individuals involved in this study, the importance of 'wanting' to re-establish links with family and home was identified as an influential factor in moving to a care home. This included the maintaining of relationships with family members and friends as well as the development of new relationships with staff (Saunders and Heliker, 2008; Lee, 2010; Sussman and Dupuis, 2012; Brandburg *et al.*, 2013; Falk *et al.*,

2013; Ryan and McKenna, 2015). Some individuals who were 'wanting to connect' with other individuals within the home identified difficulty in developing relationships, citing frailty as an inhibiting factor (Lee *et al.*, 2013). In addition, developing interpersonal relationships with staff was perceived both positively, 'they treat you like one of their own', and less favourably, 'they just do what they have to', illustrating less-meaningful relationships (Eika *et al.*, 2014). The significance of relationships is highlighted within the systematic review of Fitzpatrick and Tzouvara (2019). The authors related potential facilitators and inhibitors that corresponded with Meleis's personal and community transition conditions within the theme of interpersonal connections and relationships for older people. These connections centred on co-residents, care facility staff, family and significant others beyond the care facility. Moreover, when considering how relationships can be created and sustained, the Senses framework of Nolan *et al.* (2006) identifies six senses that are seen as prerequisites for good relationships within the context of care and service delivery, and that essentially good care can only be delivered when the 'senses' are experienced by all the groups involved. The Senses framework recognises the importance of each person in a relationship experiencing a sense of significance and feeling that they matter as a person.

Research has identified that following care home admission, individuals can lose their previous social networks and are unable to create new ones (Zamanzadeh *et al.*, 2016) and are at risk of feeling lonely and isolated (Brownie *et al.*, 2014). Moreover, it is recognised that care staff have an important role to play in encouraging new individuals to develop new relationships (Cooney, 2012; Križaj *et al.*, 2018). Conversely, Eika *et al.* (2014) stated that staff lacked awareness about the impact of the transition for the older person and their next of kin when moving to a care home. Moreover, staff must be aware of the feelings surrounding the move for both the individual and their families, such as missing loved ones and loneliness (Ellis and Rawson, 2015). Therefore, care home staff and family have the potential to support each individual's identity by maintaining relationships and promoting new social connections. This is in keeping with the guidelines of the National Institute for Health and Care Excellence (2015) which indicate that an individual's care plan should include ordinary activities outside the home to encourage participation in the community, reduce social isolation, and build personal confidence and emotional resilience.

The findings from this study clearly identify that for the majority of individuals the first four- to six-week period following entry to a care home was unsettling, and for some an upsetting experience. This study is significant because the data were collected in the early post-relocation phase and there is limited research that has explored the experiences and perspectives of older people during this crucial time period. Moving home has already been identified as a major life stressor for an older person (Ellis, 2010; Brandburg *et al.*, 2013; Sury *et al.*, 2013; Ryan and McKenna, 2015). Our study has identified that individuals report having experienced a loss of autonomy, independence and identity, making adjustment to life in a care more challenging, with individuals trying to cope with new familiarities and care routine practices with little direction or guidance (Bradshaw *et al.*, 2012; Cooney, 2012; Brandburg *et al.*, 2013; Riedl *et al.*, 2013; Ericson-Lidman *et al.*, 2014; Križaj *et al.*, 2018).

### Conclusion

It is very important that individuals who move to a care home are enabled to lead full and purposeful lives, and to realise their ability and potential. Maintaining continuity between the person's past and present role is an important factor in the adaption process. Within this study, care home staff were primarily perceived as providers of health-care delivery only and not as people with whom to develop relationships. It is important that both care home staff and individuals actively seek out opportunities for engagement with the wider community. Care home managers should be willing to look beyond traditional models of support and seek voluntary/community organisations to undertake personalised social care support. 'My Home Life' is an international initiative that aims to promote quality of life and positive change in care homes for older people. Creating a sense of community is at the heart of 'My Home Life', not only between residents, relatives and staff but also between care homes and their local communities through community engagement events and inter-generational activities. It is through connection with family and friends, and by engaging with communities, that wellbeing can be enhanced and feelings of 'Waiting and Wanting' minimised. Key recommendations from this study include the need to raise awareness of the significance of this critical time period and to amend policy and practice accordingly. This could include the development of a bespoke induction programme for each new resident facilitated by a senior member of the care home staff with overall responsibility for working in partnership with individuals and families, in addition to the broader health and social care team. The uniqueness and intrinsic value of individuals should be acknowledged in partnership with the individual and their relatives that includes their values and preferences in terms of physical and psychological safety and promoting independence. The promotion of maximum independence and rehabilitation should be afforded by all care staff taking account of advice and recommendations from relevant health and social care professionals to support a more positive transition for new residents, relatives and care home staff. Therefore, it is imperative that individual and human rights are safeguarded and actively promoted within the context of services provided by the home and an individual should have access to all the information and advice they need to make informed decisions, including advocacy services.

### Limitations of study

It is recognised that 70 per cent of people in care homes have dementia or severe memory problems (Alzheimer's Society, 2019). The exclusion of older people with cognitive impairment may be seen as a limitation of this study. However, as the study was carried out over a 12-month period and relied on participants' ability to recall and reflect on their experiences in an interview situation, it was important to select participants who would ensure that the residents' voice was heard as this is often absent from this type of research.

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## References

- Alzheimer's Society (2019) *Facts for the Media*. London: Alzheimer's Society. Available at <https://www.alzheimers.org.uk/about-us/news-and-media/facts-media>.
- Backhouse T, Kenkmann A, Lane K, Penhale B, Poland F and Killett A (2016) Older care-home residents as collaborators or advisors in research: a systematic review. *Age and Ageing* **45**, 337–345.
- Bland M (2005) The challenge of feeling 'at home' in residential aged care in New Zealand. *Nursing Praxis in New Zealand* **21**, 4–12.
- Bradshaw S, Playford E and Riazi A (2012) Living well in care homes: a systematic review of qualitative studies. *Age and Ageing* **41**, 429–440.
- Brandburg GL (2007) Making transition to nursing home life: a framework to help older adults adapt to the long-term care environment. *Journal of Gerontological Nursing* **33**, 50–56.
- Brandburg G, Symes L, Mastel-Smith B, Hersch G and Walsh T (2013) Resident strategies for making a life in a nursing home: a qualitative study. *Journal of Advanced Nursing* **69**, 862–874.
- Bridges W (2004) *Transitions: Making Sense of Life's Changes*. Cambridge, MA: Da Capo Press.
- Brownie S, Horstmanshof L and Garbutt R (2014) Factors that impact individuals' transition and psychological adjustment to long-term aged care: a systematic literature review. *International Journal of Nursing Studies* **51**, 1654–1666.
- Bull MJ and McShane RE (2008) Seeking what's best during the transition to adult day health services. *Qualitative Health Research* **18**, 597–605.
- Chin L and Quine S (2012) Common factors that enhance the quality of life for women living in their own homes or in aged care facilities. *Journal of Women and Ageing* **24**, 269–279.
- Clarke L and Bennett E (2013) 'You learn to live with all the things that are wrong with you': gender and the experience of multiple chronic conditions in later life. *Ageing & Society* **33**, 342–360.
- Cooney A (2012) 'Finding home': a grounded theory on how older people 'find home' in long-term care settings. *International Journal of Older People Nursing* **7**, 188–199.
- Corbin J and Strauss A (2008) *Basics of Qualitative Research*, 3rd Edn. Thousand Oaks: CA: Sage.
- Custers AF, Westerhof GJ, Kuin Y, Gerritsen DL and Riksen-Walraven JM (2012) Relatedness, autonomy, and competence in the caring relationship: the perspective of nursing home individuals. *Journal of Aging Studies* **26**, 319–326.
- Department of Health, Social Services and Public Safety (2006) *Safeguarding Vulnerable Adults Regional Policy & Guidance*. Belfast: Department of Health, Social Services and Public Safety.
- Eika M, Espnes GA and Hvalvik S (2014) Nursing staff's actions during older residents' transition into long-term care facility in a nursing home in rural Norway. *International Journal of Qualitative Studies on Health and Well-being* **9**, 24105.
- Ellis JM (2010) Psychological transition into a residential care facility: older people's experiences. *Journal of Advanced Nursing* **66**, 1159–1168.
- Ellis JM and Rawson H (2015) Nurses' and personal care assistants' role in improving the relocation of older people into nursing homes. *Journal of Clinical Nursing* **24**, 2005–2013.
- Ericson-Lidman E, Larsson LL and Norberg A (2014) Caring for people with dementia disease (DD) and working in a private not-for-profit residential care facility for people with DD. *Scandinavian Journal of Caring Sciences* **28**, 337–346.

- Falk H, Wijk H, Persson L and Falk K (2013) A sense of home in residential care. *Scandinavian Journal of Caring Sciences* 27, 999–1009.
- Fitzpatrick JM and Tzouvara V (2019) Facilitators and inhibitors of transition for older people who have relocated to a long-term care facility: a systematic review. *Health and Social Care in the Community* 27, e57–e81.
- Folstein MF, Folstein SE and Mchugh PR (1975) Mini-mental state. A practical method for grading cognitive state of patients for the clinician. *Journal of Psychiatry Res* 12, 189–198.
- Fraher A and Coffey A (2011) Older people's experiences of relocation to long-term care. *Nursing Older People* 23, 23–27.
- Grant J, Brutscher PB, Kirk S, Butler L and Wooding S (2009) *Capturing Research Impacts: A Review of International Practice*. Cambridge: RAND Europe.
- Heliker D and Scholler-Jaquis A (2006) Transition of new residents: basing practice on residents' perspective. *Journal of Gerontological Nursing* 32, 34–42.
- Holtslander LF and Dugleby WD (2009) The hope experience of older bereaved women who cared for a spouse with terminal cancer. *Qualitative Health Research* 19, 388–400.
- Hutchinson S, Hersch G, Davidson HA, Chu AYM and Mastel-Smith B (2011) Voices of elders: culture and person factors of residents admitted to long-term care facilities. *Journal of Transcultural Nursing* 22, 397–404.
- International Council of Nurses (2006) *Code of Ethics for Nurses*. Available at <http://www.icn.ch/about-icn/code-of-ethics-for-nurses/>.
- Iwaswi C, Goldenberg D, Macmaster E, McCutcheon S and Bol N (1996) Residents' perspectives of their first 2 weeks in a long-term care facility. *Journal of Clinical Nursing* 5, 381–388.
- Johnson R and Bibbo J (2014) Relocation decisions and constructing the meaning of home: a phenomenological study of the transition into a nursing home. *Journal of Aging Studies* 30, 56–63.
- Johnson R, Popejoy L and Radina M (2010) Older adult's participation in nursing home placement decisions. *Clinical Nursing Research* 19, 358–375.
- Keister KJ (2006) Predictors of self-assessed health, anxiety, and depressive symptoms in nursing home residents at week 1 post relocation. *Journal of Aging and Health* 18, 722–742.
- Komatsu M, Hamahata A and Magilvy JK (2007) Coping with the changes in living environment faced by older persons who relocate to a health-care facility in Japan. *Japan Journal of Nursing Science* 4, 27–38.
- Križaj T, Warren A and Slade A (2018) 'Holding on to what I do': experiences of older Slovenians moving into a care home. *The Gerontologist* 58, 512–520.
- Lee DTF (1999) Transition to residential care: experiences of elderly Chinese people in Hong Kong. *Journal of Advanced Nursing* 30, 1118–1126.
- Lee DTF (2001) Perceptions of Hong Kong Chinese elders on adjustment to residential care. *Journal of Interprofessional Care* 15, 235–244.
- Lee DTF (2010) Predictors of adjustment to nursing home life of elderly residents: a cross-sectional survey. *International Journal of Nursing Studies* 47, 957–964.
- Lee DTF, Woo J and Mackenzie A (2002) A review of older people's experiences with residential care placement. *Journal of Advanced Nursing* 37, 19–27.
- Lee V, Simpson J and Froggart K (2013) A narrative exploration of older people's transitions into residential care. *Aging and Mental Health* 17, 48–56.
- Lincoln Y and Guba E (1985) *Naturalistic Inquiry*. Newbury Park, CA: Sage.
- Lindley S and Wallace J (2015) Placing in age: transitioning to a new home in later life. *ACM Transactions on Computer-Human Interaction* 22, 20.
- Maz J (2013) Employing grounded theory approach: core characteristics. *British Journal of Cardiac Nursing* 8, 453–458.
- Meleis AI (2010) *Transitions Theory – Middle Range and Situation Specific Theories in Nursing Research and Practice*. New York, NY: Springer.
- Minhat HS, Rahmah MA and Khadijah S (2013) Continuity theory of ageing and leisure participation among elderly attending selected health clinics in Selangor. *International Medical Journal Malaysia* 12, 51–58.

- Moore KD and Ryan AA (2017) *The Lived Experiences of Nursing Home Residents in the Context of the Nursing Home as Their 'Home'. A Grounded Theory Study* (Main Report). Ulster University and Nursing Homes Ireland. Ulster University.
- Morse JM (2009) Exploring transitions. *Qualitative Health Research* **19**, 431.
- Morse JM, Stern PN, Corbin J, Bowers B, Charmaz K and Clarke AE (2009) *Developing Grounded Theory: The Second Generation*. Walnut Creek, CA: Left Coast Press.
- Munhall PL (2012) *Nursing Research. A Qualitative Perspective*, 5th Edn. edn, Sudbury, MA: Jones & Bartlett Learning, C2012.
- National Institute for Health and Care Excellence (2015) *Transition Between Inpatient Hospital Settings and Community or Care Home Settings for Adults with Social Care Needs* (NG27). Available at <https://www.nice.org.uk/guidance/ng27/chapter/Recommendations#discharge-from-hospital>.
- Nolan MR, Hanson E, Magnusson L and Anderson B (2003) Gauging quality in constructivist research: the Aldre Vast Sjuharadmodel revisited. *Quality in Ageing* **4**, 22–27.
- Nolan M, Brown J, Davies S, Nolan J and Keady J (2006) *The SENSES Framework: Improving Care for Older People Through a Relationship-centred Approach*. Sheffield, UK: University of Sheffield.
- O'Neill M, Ryan A, Tracey A and Laird EA (2020) 'You're at their mercy': older peoples' experiences of moving from home to a care home: a grounded theory study. *International Journal of Older People Nursing* **15**, e12305.
- Österlind J, Ternstedt BM, Hansebo G and Hellström I (2017) Feeling lonely in an unfamiliar place: older people's experiences of life close to death in nursing home. *International Journal of Older People Nursing* **12**, e12129.
- Paddock K, Brown Wilson C, Walshe CE and Todd C (2019) Care home life and identity: a qualitative case study. *The Gerontologist* **59**, 655–664.
- Porter EJ and Ganong L (2005) Older widows' speculations and expectancies concerning professional home-care providers. *Nursing Ethics* **12**, 507–521.
- QSR International (2018) *NVivo Qualitative Data Analysis*, Version 12. Melbourne: QSR International.
- Regulation and Quality Improvement Authority (2020) *Guidance for the public clicks into the definition of a nursing and residential home*. Available at <https://www.rqia.org.uk/guidance/guidance-for-the-public/frequently-asked-questions-for-public/>.
- Riedl M, Mantovan F and Them C (2013) Being a nursing home resident: a challenge to one's identity. *Nursing Research and Practice* **2013**, 932381.
- Ryan A and McKenna H (2015) 'It's the little things that count'. Families' experience of roles, relationships and quality of care in nursing homes. *International Journal of Older People Nursing* **10**, 38–47.
- Saunders JC and Heliker D (2008) Lessons learned from 5 women as they transition into assisted living. *Geriatric Nursing* **29**, 369–375.
- Strauss A and Corbin J (1990) *Basics of Qualitative Research*. Thousand Oaks, CA: Sage.
- Strauss A and Corbin J (1998) *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*, 2nd Edn. Thousand Oaks, CA: Sage.
- Sullivan GJ and Williams C (2017) Older adult transitions into long-term care. *Journal of Gerontological Care* **43**, 41–49.
- Sullivan L and Willis DG (2018) Towards changing the long-term care (LTC) paradigm: explicating the concept of thriving in older adults living in LTC. *Issues in Mental Health Nursing* **39**, 388–397.
- Sury L, Burns K and Brodaty H (2013) Moving in: adjustment of people living with dementia going into a nursing home and their families. *International Psychogeriatrics* **25**, 867–876.
- Sussman T and Dupuis S (2012) Supporting a relative's move into long-term care: starting point shapes family members' experiences. *Canadian Journal on Aging* **31**, 395–410.
- Sussman T and Dupuis S (2014) Supporting individuals moving into long-term care: multiple layers shape individuals' experiences. *Journal of Gerontological Social Work* **57**, 438–459.
- Tanner D (2010) *Managing the Ageing Experience: Learning from Older People*. Bristol, UK: Policy Press.
- Tsai HH and Tsai YF (2008) A temporary home to nurture health: lived experiences of older nursing home residents in Taiwan. *Journal of Clinical Nursing* **17**, 1915–1922.
- Walker E and McNamara B (2013) Relocating to retirement living: an occupational perspective on successful transitions. *Australian Occupational Therapy Journal* **60**, 445–453.

- Walker CA, Curry LC and Hogstel MO** (2007) Relocation stress syndrome in older adults transitioning from home to a long-term care facility: myth or reality? *Journal of Psychosocial Nursing and Mental Health Services* **45**, 38–45.
- Wiersma E and Dupuis SL** (2010) Becoming institutional bodies: socialization into a long-term care home. *Journal of Aging Studies* **24**, 278–291.
- Wilson SA** (1997) The transition to nursing home life: a comparison of planned and unplanned admissions. *Journal of Advanced Nursing* **26**, 864–871.
- Wilson CB and Clissett P** (2011) Involving older people in research: practical considerations when using the authenticity criteria in constructivist inquiry. *Journal of Advanced Nursing* **67**, 677–686.
- Zamanzadeh V, Rahmani A, Pakpour V, Chenoweth LL and Mohammadi E** (2016) Psychosocial changes following transition to an aged care home: qualitative findings from Iran. *International Journal of Older People Nursing* **12**, e12130.

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#### **4.12 Interview Three (Four to five months post move)**

All interviews at this timepoint were conducted between August 2017 and December 2018. Semi-structured interviews were conducted with individuals (n=17) from eight care homes across the study site. The audio taped interviews were transcribed verbatim with each interview lasting approximately 60-75 minutes. Field notes were taken to record rich contextual information. In addition to categories identified in Figure 4.6, independence, autonomy and undertaking meaningful and purposeful activities were still identified by participants albeit to a lesser extent as having an impact on their quality of life within the care homes. It was noted that there were widespread differences in the provision of activities across care home facilities. Some care homes offered residents purposeful opportunities to pursue meaningful activities while others did not. Some participants expressed the view that days were long and boring which left them feeling unsatisfied and disengaged. Participants reflected that they were most likely to participate in activities which were designed to include their own individual interests.

#### **4.13 Interview Four (Nine to twelve months post move)**

The final round of interviews was conducted between April 2018 and May 2019. Semi-structured interviews were undertaken with individuals (n=17) from eight care homes across the study site. The audio taped interviews were transcribed verbatim with each interview lasting approximately 60 minutes. As with interview three, findings at the end of the first year in the care home indicated that some participants felt constrained by rules, regulations, and routine. They perceived themselves as being 'one of a number' rather than an individual and this impacted negatively on their



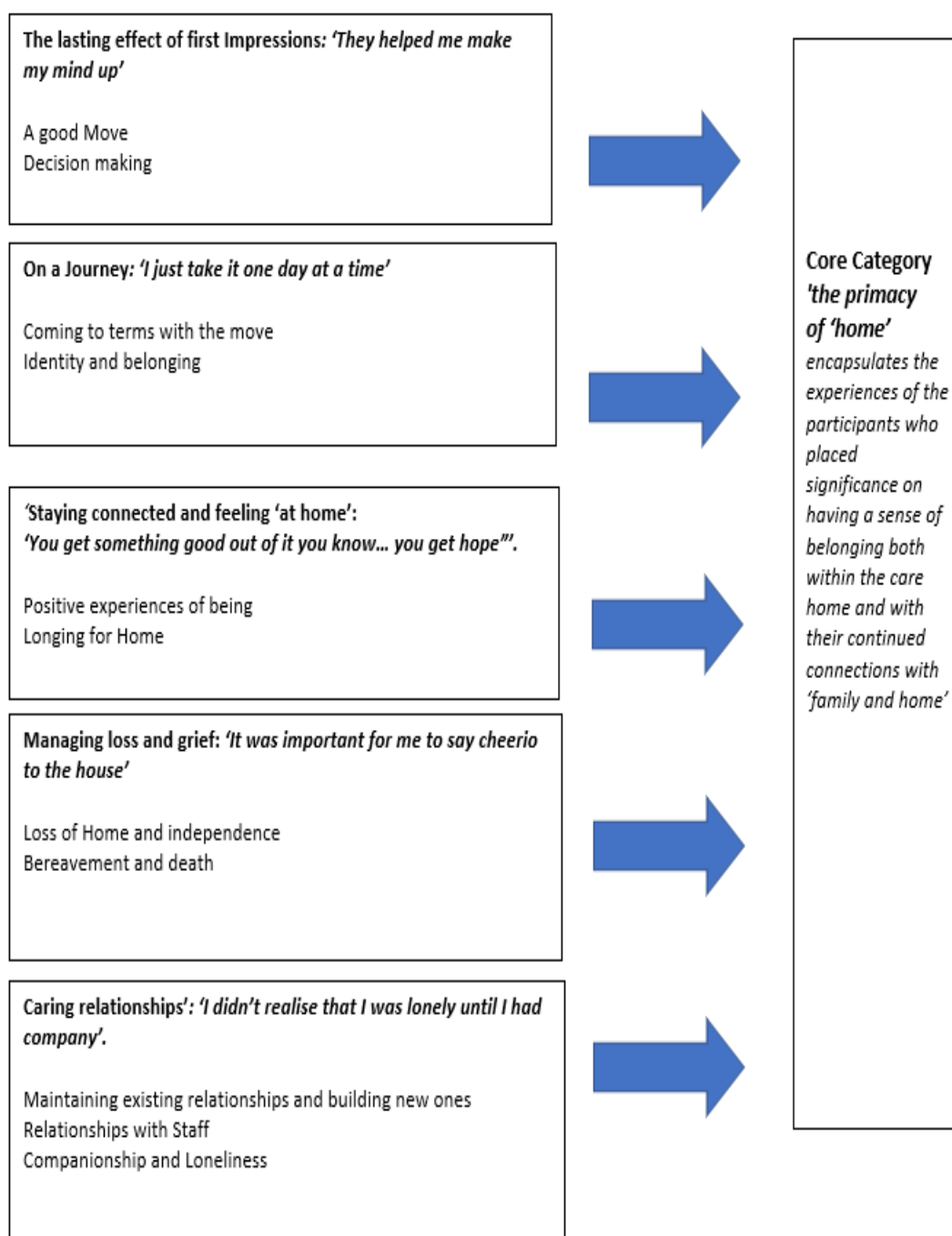
choice and independence. When independence was perceived to be hindered, some participants began to doubt their own capabilities, which had an impact on their self-confidence and emotional well-being.

#### **4.14 Concepts, categories, and core category**

Data analysis for interviews three and four, although analysed separately, are presented together as there was an insufficient difference in the findings and categories to warrant a separate section. As with previous interviews, the data analysis was informed by open, axial, and selective coding principles as espoused by Corbin and Strauss (2008). Simultaneous data collection and constant comparative analysis were undertaken and repeated until theoretical saturation was achieved when no new categories were identified, and until new instances of variation for existing categories ceased to emerge. The final stage of selective coding was the process of integrating and refining categories, a core category was identified that related to the other categories, validating those similarities and relationships (Strauss and Corbin 1998). Identified categories were: 1) The lasting effect of first Impressions: *'They helped me make my mind up'*, 2) On a Journey: *'I just take it one day at a time'*, 3) Staying connected and feeling 'at home': *'You get something good out of it you know...you get hope'*, 4) Managing loss and grief: *'It was important for me to say cheerio to the house'* and 5) Caring relationships: *'I didn't realise that I was lonely until I had company'*. The five emergent categories connected to and formed the basis of the core category the *'The Primacy of 'Home'* which captures the experiences' of participants who placed significance on maintaining their identity and having a sense of belonging to their new home and care home family in addition to their pre-existing home and

family in the community. Figure 4.5 the relationship of major categories to each other and to the core category.

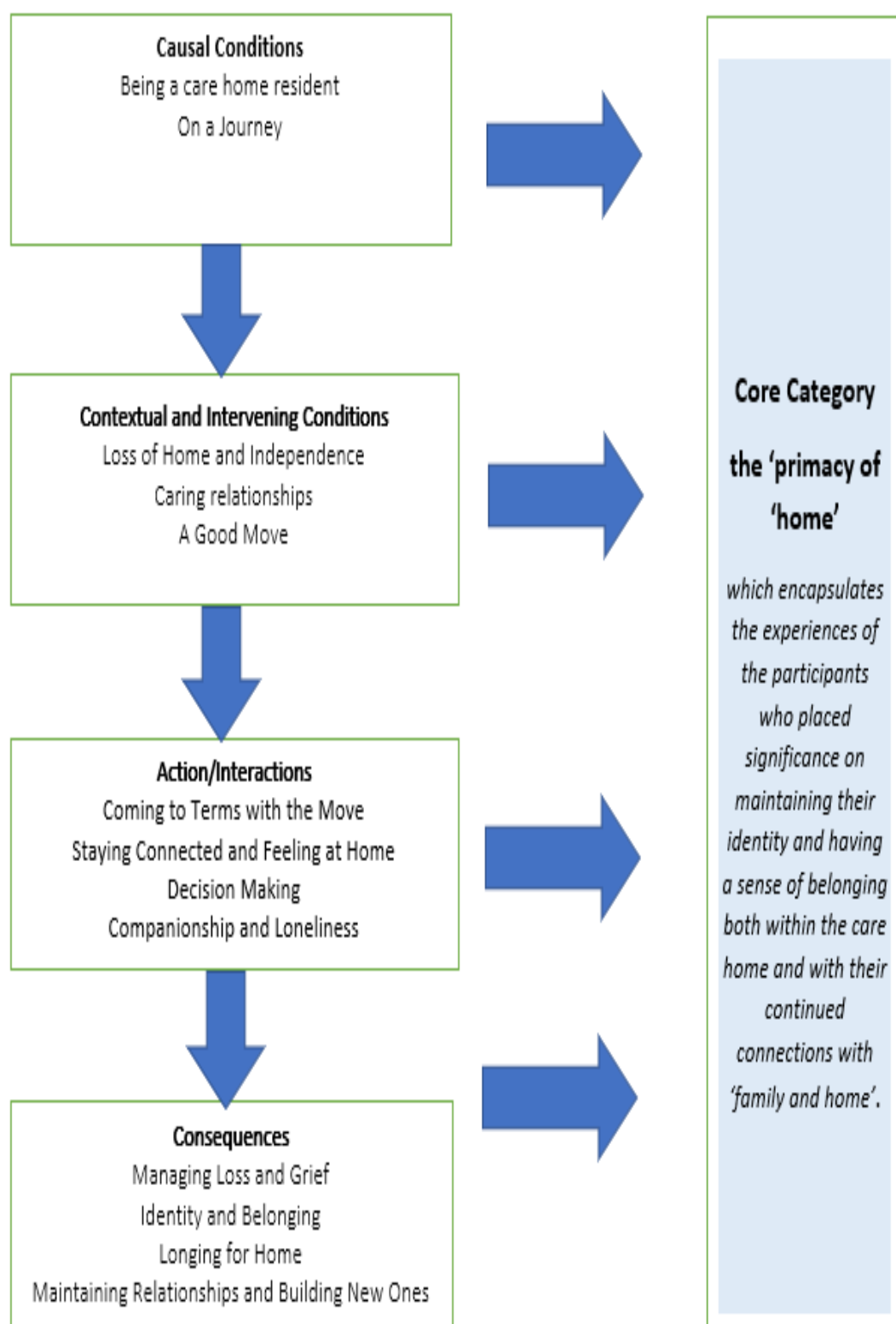
**Figure 4.5:** Relationship of major categories to each other and to the core category



#### 4.15 Paradigm Model Three

The contextual and causal conditions for individuals at interviews three and four are concerned with being a care home resident on a journey of transition. The intervening conditions are associated with experiences of loss of home and independence, caring relationships and if the move was deemed to be a positive one as shown within actions/interactions. The way in which individuals come to terms with the move are seen with actions/interactions as in staying connected to home and family while developing new relationships with 'care home family' which demonstrates the connection to the core category '*The Primacy of 'Home'*'. Within this setting, individuals placed substantial meaning on preserving their identity and finding connections both within the care home and with 'family and home'. The consequences at this time point were as a result of the actions/interactions resulting in individuals trying to manage their loss and grief, maintaining relationships, and building new ones. The core category connects to emergent categories which included accounts of individuals' experiences of maintaining their sense of Identity, and connectedness with 'family and home'. See Figure 4.6 for Paradigm Model Interviews Three and Four.

**Figure 4.6: Paradigm Model Three**



#### 4.16 **‘The Primacy of ‘Home’: An exploration of how older adults’ transition to life in a care home towards the end of the first year (Paper Three)**

This paper reports key findings pertaining to the experiences of older people between five months and twelve months after the move to a care home. Identified categories were: 1) The lasting effect of first Impressions: *‘They helped me make my mind up’* 2) On a Journey: *‘I just take it one day at a time’*, 3) Staying connected and feeling ‘at home’: *‘You get something good out of it you know...you get hope’*, 4) Managing loss and grief: *‘It was important for me to say cheerio to the house’*, and 5) Caring relationships: *‘I didn’t realise that I was lonely until I had company’*. Together these five categories formed the basis of the core category **‘The Primacy of ‘Home’** which encapsulates the experiences of the participants who placed significance on maintaining their identity and having a sense of belonging both within their own home and within the care home. Participants spoke about the importance of maintaining connection to their own home, family, friends, and community which enabled them to move towards a positive adaptation and acceptance of living in the care home. A detailed discussion of these findings is presented in Paper Three.

**Paper Three:** O'Neill M, Ryan A, Tracey A and Laird EA (2020) ‘The Primacy of ‘Home’: An exploration of how older adults’ transition to life in a care home towards the end of the first year. *Health and Social Care in the Community*. (Appendix 1)

## **The 'Primacy of 'Home': An exploration of how older adults transition to life in a care home towards the end of the first year.**

### **Abstract**

This grounded theory study sought to explore how older adults' experience the transition from living at home to a care home with a specific focus on the latter part of the first year of the move. The study was carried out within a large Health Trust in the UK between August 2017 and May 2019. Purposive sampling was used in the initial stages of data collection. Thereafter and consistent with grounded theory methodology theoretical sampling was employed to undertake semi-structured interviews with 17 individuals from eight care homes between five and twelve months after the move. This paper reports five key categories which were: 1) The lasting effect of first Impressions '*They helped me make my mind up*' 2) On a Journey '*I just take it one day at a time*', 3) Staying connected and feeling 'at home' '*You get something good out of it you know...you get hope*'. 4) Managing loss and grief '*It was important for me to say cheerio to the house*' and 5) Caring relationships '*I didn't realise that I was lonely until I had company*'. Together these five categories formed the basis of the core category the 'Primacy of 'Home' which participants identified as a place they would like to feel valued, nurtured and have a sense of belonging. This study identifies that it is important for individual preferences and expectations to be managed from the outset of the move. Individuals and families need to be supported to have honest and caring conversations to promote acceptance and adaptation to living in a care home while continuing to embrace the heart of 'home'. Key recommendations from this study include the need to raise awareness of the significance of the ongoing psychological and emotional well-being needs of older people which should be considered in policy directives and clinical practice.

### **What is known about this topic?**

- The extent to which individuals exercise control over the decision to move to a care home is recognised as an important determinant of their relocation experience.
- Most studies report that care home environments can be restrictive, therefore making adjustment and adaptation more challenging.
- There is a dearth of research on the extent to which residents can be facilitated to feel 'at home' in a care home environment

### **What this paper adds**

- Positive adaptation is connected to older peoples' perceived quality of life, continued connection to home, family and community, and having opportunities to develop meaningful relationships with staff and other residents.
- Facilitating difficult and caring conversations with individuals and their families is required to manage individual expectations of the move to promote a positive adaptation process.
- Failure to engage early with these difficult conversations can negatively impact on the adaptation process over the course of the first year of life in a care home.
- Older people do not always have existing social supports to cope with bereavement and loss in the care home which has a significant impact on their psychological well-being.

**Key words: Older People, Adaptation, Quality of life, Care Home, Transitions, Grounded Theory.**

## **The 'Primacy of 'Home': An exploration of how older adults transition to life in a care home towards the end of the first year.**

### **1. Introduction**

The experience of aging may require older people to make transitions in their living environments, either by adaptations to current homes or through relocations to more supportive environments (Perry et al., 2013). 'Aging in place' relates to an older person's sense of identity through their independence and autonomy alongside caring relationships and roles in the places they live (Wiles et al., 2012). Older people want choices about where and how they age in place, therefore the importance of involving 'the person' in making the decision to move and having a choice of a care home is significant. Furthermore, having a sense of attachment or connection to their existing home or community maintains security and familiarity (Wiles et al., 2012; O'Neill et al., 2020).

The extent to which individuals, who need 24 hour care exercise control over the decision to move to a care home is recognized as an important determinant of their relocation experience (Chao et al., 2008; Johnson et al., 2010; Fraher & Coffey, 2011; Lee et al., 2013; Ryan & McKenna 2015, O'Neill et al., 2020). Individuals have reported that greater involvement in the decision to move to a care home could have eased the negative feelings surrounding the move (Nwe et al., 2011; Sury et al., 2013). Similarly, whether the decision to move was made by the individual or imposed by others adversely affects residents' transition experience and their related grief reactions to the move and to the loss of their home (Crawford et al., 2015; Priddy et al., 2019; Zizzo et al., 2020).

Most studies report that care home environments can be restrictive, therefore making adjustment and adaptation more challenging for the individual as feelings of institutionalisation can occur (Tsai H-H and Tsai Y-F 2008; Cooney 2012; Bradshaw 2012; Ericson-Lidman et al., 2015; Krizaj et al., 2016). In contrast to the negative assertions, the literature also suggests that the potential benefits for older people entering into care homes include improved self-worth, morale, physical functioning, feeling less lonely and feeling more secure (Wadensten 2007; Katz et al., 2011; Lee et al., 2013; O'Neill et al., 2020). A major challenge associated with the transition into a care home is the loss of the individual's home, therefore threatening identity, belonging and sense of self (Westin et al., 2012; Lee et al., 2013; Brownie et al., 2014). Home is not only fundamental to a person's self-identity and social relationships, but homely environments are essential to promote recovery, well-being and quality of life (Molony 2010; Rioux and Werner 2011; Bokerman et al., 2012). Additionally, individuals may lose previous social and communication networks (Zamanzadeh et al., 2016) putting them at risk of feeling lonely and isolated (Brownie et al., 2014).

Research undertaken by Cooney (2012) identified four categories as significant to 'finding home' in long-term care settings. These were: 'continuity', 'preserving personal identity', 'belonging' and 'being active and working'. What made it simpler or more problematic for older people to 'find home' was either unique to the individual (adaptive responses, expectations and/or past experiences) or at an institutional level (ethos of care, institutional culture, environment of setting).

Rijnaard et al (2016) undertook a systematic review of seventeen mainly qualitative research studies. The aim of the review was to provide an overview of factors influencing the 'sense of home' of older adults residing in the nursing home. They found that a nursing home resident's 'sense of home' was influenced by fifteen factors, divided into three themes: (1) psychological factors (sense of acknowledgement, preservation of one's habits and values, autonomy and control, and coping); (2) social factors and activities (interaction and relationship with staff, residents, family, friends, and pets); and (3) the built environment (private space and quasi-) public space, personal belongings, technology, "look and feel" interior design and the general maintenance, and 'the outdoors and location' which relates to the home's outdoor space and the neighbourhood at large. Similar findings were reported in a systematic review by Fitzpatrick and Tzouvara (2019) which used Meleis's Theory of Transition (2010) to explore facilitative and inhibitive influences on older peoples' transition to long-term care. Data synthesis of thirty-four studies identified that the transition featured potential personal and community focused facilitators and inhibitors which were mapped to four themes: 'resilience of the older person', 'interpersonal connections and relationships,' 'this is my new home', and 'the care facility as an organisation'.

Complex and multidimensional factors can influence the adaption process for older people when relocating to a care home (Bradshaw et al., 2012; Brownie et al., 2014; Krizaj et al., 2016; Roy et al., 2018). There is a dearth of research on the extent to which residents can be facilitated to feel 'at home' in a care home environment, particularly during the first year of the move. This study sought to address this imbalance.

#### Aim

To explore how older adults' experience the transition from life at home to life in a care home with a specific focus on the latter part of the first year of the move.

## 2. Methods

### 2.1 Study Design

A grounded theory approach, consistent with the work of Strauss and Corbin (1990, 1998), was chosen as it facilitated the development of a new perspective on the experiences of older people living in a care home with a particular focus on the latter part of their first year after the move. Grounded theory is recommended when investigating social problems or situations to which people must adapt (Corbin and Strauss, 2008; Morse et al., 2009; Maz, 2013). Grounded theory is an ideal methodology to understand actions and processes through transitions (Morse 2009) and has been used by qualitative researchers to study processes engaged in by service users (Grant et al., 2009). A semi-structured interview schedule was designed to stimulate discussion of individuals' perceptions, thoughts and feelings about their experiences of living a care home during this specific time period.



## 2.2 Participants and recruitment

The study was carried out within a large Health and Social Care Trust in the UK which provides health and social care services including 1,800 residential and nursing home placements to a population of approximately 300,000 people across rural and urban areas. Purposive sampling was used to recruit participants for the initial interviews. Thereafter and consistent with grounded theory methodology, theoretical sampling was employed to recruit a sample of 17 individuals who had resided in a care home for a time period of between 5 and 12 months. The five-month inclusion criterion was important as this was consistent with the time frame for confirmation of permanent residency. Residents who met this criterion were identified by community-based care managers and through direct contact with care home managers.

### **Insert Table 1 Characteristics of the participants and details of admission.**

## 2.3 Data collection

Detailed information about research study was presented in writing and verbally to each participant and a binder provided which included information about study printed in large font with contact details of the research team. Information details included how to lodge a complaint, a consent form, and the procedure to be followed in specific situations, for example, if the older person became upset or distressed. A tape-recording of this information was made available to visually impaired residents if required. Individual face-to-face interviews were arranged at a time convenient for each participant. All interviews were conducted between August 2017 and May 2019. Semi-structured interviews were conducted with 17 individuals from eight care homes across the study site. Written consent for each interview was provided by participants. The audio taped interviews were transcribed verbatim with each interview lasting approximately 60 minutes. Field notes were taken by the interviewer. Consistent with a grounded theory approach, the semi-structured interviews provided both focus and flexibility (Corbin & Strauss, 2008). Simultaneous data collection and constant comparative analysis were repeated until data saturation was accomplished along with the advancement of theoretical concepts. The interview schedule evolved commensurate with category and subcategory dimensions using grounded theory approach

(see appendix 1)

## 2.4 Ethical considerations

Ethical approval for the study was initially obtained through the ethics committee of the university leading the research. Ethical approval was subsequently gained from the regional ethics committee and from the health and social care trust where the study was based. The researcher made concerted efforts through recruitment to ensure that the voices and experiences of older people were given due

attention and that participants themselves found their involvement meaningful (Dewing, 2009) . Minimal or no cognitive impairment as defined by the Mini Mental State Examination (MMSE >24) was a criterion for participant's inclusion in the study. The study was carried out over a 12 month period and relied upon participants ability to recall and reflect upon their experiences over this time frame. By undertaking the MMSE prior to interview the researcher was able to ascertain participant's cognitive ability prior to each interview and any changes over time. Informed consent was provided by each participant with additional consent obtained to use a digital recorder for the interviews. Assurances of confidentiality and anonymity were provided and supported by the allocation of pseudonyms in the presentation of the study and its findings.

## 2.5 Data Analysis

NVivo 12 qualitative data analysis programme software (QSR International, 2012) facilitated the organisation, management and retrieval of transcribed interviews and field notes and provided tools for coding, categorising and linking qualitative data. Data analysis was informed by open, axial and selective coding principles as espoused by Corbin and Strauss (2008). Simultaneous data collection and constant comparative analysis were undertaken and repeated until theoretical saturation was achieved when no new categories were identified, and until no new instances of variation for existing categories ceased to emerge. The final stage of selective coding was the process of integrating and refining categories, a core category was identified that related to the other categories, validating those similarities and relationships (Strauss and Corbin, 1998).

## 2.6 Ensuring Rigour

The initial interviews were recorded and checked to ensure the rigour of the data collection procedures. The constant comparative analysis of emerging data facilitated the verification of findings and minimised the likelihood of personal bias. The process of theoretical sampling continued until the emerging concepts and categories reached saturation. During the open and axial coding stages, two members of the research team (MON & AT) independently viewed the original uncoded manuscripts and confirmed themes thus ensuring that interpretations represented the experiences of the individuals. After the selective coding process, trustworthiness of the data was enhanced by all the research team who reviewed themes and discussed alternative interpretations of the data to maximize credibility, dependability and confirmability (Lincoln and Guba 1985). In keeping with one of the tenets of grounded theory (Corbin and Strauss, 2008), individuals' own language at all levels of coding was used to further ground theory construction and add to the credibility of findings.

### *Profile of Participants*

The seventeen participants in this study comprised of ten females and seven males with an average age of 83.3 years. Seven participants were admitted directly from hospital. Four of these individuals were female and three were male. In comparison, six female and four male participants were admitted to the care home directly from home (one female and one male moved to the care home when their respective carers became ill). The main reasons cited for prompting the relocation to a care home were deterioration in physical health (n=11), recent bereavement (n=3) and no-one to take care of me/changing family circumstances (n=3). The majority of the individuals (n=15) did not visit the care home prior to the move; one participant chose the home previously for his wife and one participant was accompanied by a social worker.

### **3. Findings**

This paper reports key findings pertaining to the experiences of older people between five months and twelve months after the move to a care home. Identified categories were: 1) The lasting effect of first Impressions: *'They helped me make my mind up'* 2) On a Journey: *'I just take it one day at a time'*, 3) Staying connected and feeling 'at home': *'You get something good out of it you know...you get hope'*, 4) Managing loss and grief: *'It was important for me to say cheerio to the house'* and 5) Caring relationships: *'I didn't realise that I was lonely until I had company'*. Together these five categories formed the basis of the core category the **'Primacy of Home'** which encapsulates the experiences of the participants who placed significance on maintaining their identity and having a sense of belonging both within the care home and with their continued connections with 'family and home'.

**Figure One** below shows the relationship of major categories to each other and to the core category.

#### **3.1 The lasting effect of first Impressions – *'They helped me make my mind up'***

A good Move- *'I was positive from the start'*.

First impressions of the move to the care home, and the home itself, were important and continued to influence participants' experiences throughout the first year of the move. Many expressed positive feelings about living in the care home from the outset of the move. This optimism was fostered by the participant, and by hospital and care home staff who promoted and endorsed the positivity of the move for the individual concerned.

*"I have always loved it here. Ever since I was told by the staff in the Hospital that I was coming here.... they told me that I would love it and I did..... Yes, and they helped me make my mind up about moving here too. Because I was struggling you know on my own and they helped me realise how hard it was trying to carry on. Aye definitely, I was positive from the start" (Kevin, 5 months).*

*"I remember that from the very beginning the staff were welcoming, they were kind and it just felt right to be here. I know it was my decision to come here but I made a good choice and I was determined to get on well" (Martha, 12 months).*

*"Well I suppose I always thought that it was like home from home here. I feel happy here, everyone is friendly, and they are good to all the people here" (Isobel, 11 months).*

#### Decision making- 'I didn't have a choice'

Up to twelve months after the move to the care home, some participants still maintained that a key factor in their feeling 'at home' was whether they were involved in the initial decision to move into the facility. Participants' comments suggested that the decision was sometimes a forced choice. Exclusion from the decision-making process and having an overall negative first impression appeared to permeate their experience of the move over the first year.

*"Well I suppose people would need to want to come here. I didn't have a choice. It would probably be easier if you had to time to get used to it. But sure, I suppose in the end it's the same outcome .... it's just that it would have been a smoother journey for me of getting here, if I had had a say in everything. No matter what, well.... you just have to give into it all in the end"* (Charles, 12 months)

*"Well, I want me and my daughter to be together. I will not settle until then, until she comes here, or I get home. Everybody is still making the decisions for me. I didn't want to come here. I feel lost and nobody cares that I am ill, I feel that this is the end"* (Mona, 11 months).

### 3.2 On a Journey - 'I just take it one day at a time'.

Coming to terms with the move 'It's not home but what can you do'.

It was evident during interviews that some participants were resigned to the fact that there was no other option for them but to be living in the care home. In some cases, they appeared to 'have come to terms with the move' voicing acceptance, resignation and ultimately contentment.

*"I mean I would want to be at home, but I can't, and this is a good place. Sure, my family can visit me, and they can come and go whenever they want to see me so, what more do I want? .... Sure, what can you do, you just have to get on with it. I will be ninety-three now in October. I am happy"* (Bernadette, 11 months)

*"I am probably getting more used to it now. It's not home but what can you do. I suppose I have to reconcile myself with being here now, it's better than being on my own so I have come to terms with living here now.....you just have to get on with it and try to make it work"* (Hugh, 5 months).

*"I just adapted myself to the place and the people. It's hard without my wife but I had to do it. Once you have done six months service here you try to kind of accept it. You get used to it I suppose. I think that it's alright living here now, it's a necessity and I get on with it, I am doing ok"* (Charles, 12 months).

For all participants getting settled into 'their new home' was a process that occurred over time and individual responses varied. There was no set time for familiarisation to begin and end.

*"I think I have settled in well now; it took a while to get used to it all, the people you know and their way of doing things, but I think that I am doing ok now"* (Anne, 5 months).

*"I love it here now; I think that I have settled in well. It is the best place for me. I couldn't be on my own. I realise that now"* (Molly, 6 months).

For other participants, their own a personal level of resilience and positive thinking promoted positive adaptation and acceptance experiences to living in the care home.

*"I think that you have got to concentrate on the positive things and try not to dwell on the negative things like a bad carer...they are not perfect"* (Andrew, 12 months).

*"I am making the best of it sure what can you do. I have my things here that's all I want, and I will be seeing out my time here, so I might as well get on with it. You have to be resilient yourself to cope with being in a care home and being on your own"* (Tony, 11 months).

Identity and belonging 'I don't feel as much of an outsider anymore'

Participants identified the significance of feeling a sense of identity and belonging within the care home and the importance of getting on with residents and care home staff.

*"I don't feel as much of an outsider anymore. I am one of the longer stay residents here now. You feel for the new people coming in that they are not yet part of the home" (Tracey, 11 months).*

*"I would say that you need to try and get involved with the staff and the other people here to help you. You need to talk to the staff and let them know what you want. It is about people making you feel welcome and that you belong here" (Charles, 5 months).*

### **3.3. Staying connected and feeling 'at home' - 'You get something good out of it you know...you get hope'.**

Twelve months after the move participants spoke about the importance of maintaining connection to their own home, family, friends and community which enabled them to move towards a positive adaptation and acceptance of living in the care home. Participants reported that they were dependant on family or friends to pursue home visits or activities outside of the home. The impact of getting a visit home on participants psychological well-being was highlighted in many of the interviews. Some participants expressed that the excitement of 'getting home' and having respite from the care home, helped in breaking the routine of daily care home life.

*"I go out to my daughter's place and home too. The neighbours are there as well you see. Mrs D\*\*\*\* and all them ones you know. So nice to see them and you feel great when you come back" (Bernadette, 11 months)*

*"My son takes me out to the town or back to the house for a while. I love getting home and I see the neighbours and friends. I always look forward to getting a run out in the car" (Tracey, 11 months).*

*"I think that people should be taken out of this house even for a while. I get home when my children come over to visit. You get something good out of it you know...you get hope" (Andrew, 5 months)*

Positive experiences of being 'Home from Home'

Others reported satisfaction with the care they received in the care home and related this to their 'own home' comparing their experiences as being in 'a home from home':

*"Well I suppose I always thought that this was like home from home when I came here. I feel happy here, everyone is friendly, and they are good to all the people here" (Isobel, 11 months).*

*"I feel just great.... as I say I just try to keep going. I am ninety-one and a half now so if god gives me life then I will keep going. And sure, it's like being in my own wee home here, with the care I get here which is so good, I am bound to keep going" (Anne, 12 months).*

Longing for Home 'I still have hope of getting home'

Despite the permanent nature of the placement, two participants yearned to go back home at some point in the future. Sean aged 60 years was admitted to the care facility from hospital following a spinal injury. He had complex health needs and was unable to be cared for at home by his wife who lives alone. Sean wanted to go home if a care package was able to be put in place. In the 12 months he was resident in the care home, he returned home for several days at key holiday periods i.e. Christmas, Easter and family occasions. The care home staff provided home care to Sean in the absence of Trust community care provision being available to ensure that Sean got home to his family. A care package for Sean to remain at home permanently has not materialised since.

*"I could never resign myself to being here for life. Hope of getting home is fading fast. The best I can think of right now is to get out for weekends. Getting home permanently, well that's the dream. I am losing hope of ever getting a care package organised to be honest. One of the impressions I get from them is that they don't consider my going home to be an option" (Sean, 12 months)*

David aged 88 years lived alone and was admitted to hospital following a fall at home. He still had hopes of returning home five months after moving to the care home, if his health becomes conducive to independent living. David stated that he could live independently if house adaptations were undertaken including servicing a stair lift. This longing for home remained, even though David had chosen the care home for himself and his wife (who moved in one year prior to David and remained a resident in the care home). At five months David had expressed dissatisfaction with perceived restrictive care practices that were influencing his independence and autonomy.

*"I still have hope of getting home, and I think if they would do something about my hands I would be away and could manage on my own with a bit of home help and then worry about everything else after I get home. I think that there are too many rules and regulations here, your life is not your own and you are not allowed to move about without having to ask for permission" (David, 5 months).*

However, at the 12-month interview, David stated that he 'could mobilise independently' and restrictions were lifted i.e. he was allowed out to garden on his own and could now mobilise independently within the care home environment. He became more content to live in the care home stating:

*"I have got my independence back again. The sanctions have been lifted. I don't think that I will ever be home again now. It has come naturally to me..... It just takes time to come to that realisation..... Things are better now" (David, 12 months).*

### **3.4 Managing loss and grief 'It was important for me to say cheerio to the house'**

Loss of Home and independence 'I can't live the life that I want to'.

Saying goodbye to home was very important for some participants. Kevin who had moved to the care home from hospital following a fall was enabled by the social worker to visit his own home on several occasions to sort out his belongings and then a solicitor facilitated his house sale.

*"It was good to go down home and get my things together. I brought everything that I wanted up here. It was important for me to say cheerio to the house, I had lived there for 34 years" (Kevin, 5 months).*

For one participant Ellen, the perceived loss of her 'independence and life' influenced her choice of staying in the care home. Ellen had originally wanted to move into sheltered housing but there were no vacancies available before or during her twelve months stay. Nine months after moving in, Ellen made plans to go to Australia to live with her daughter.

*"I am not happy here. I have no independence and I can't live the life that I want to. I can't live here for the rest of my life. I have to have a life. Lots of people live here, they haven't got a life, they're here to stay. I'm not ready for that yet" (Ellen, 11 months).*

Bereavement and death 'death is part of life and important to all of us'

The impact of the first year of life in a care home was, for some participants, compounded by the death of close family members before and after the move. For health care practitioners, death is an inevitable part of working in a care home, but this study suggests that the grief and loss experienced by residents after the death of fellow residents is not always understood by staff.

*"There is a change of atmosphere here when someone dies. You miss some more than others, one man called Max he was outgoing, he didn't mind telling you what he thought.... (laughs), we really missed him when he went (Charles, 5 months).*

Participants reported experiencing a range of emotions when someone died within the home. They reported feeling 'upset and annoyed' when a member of their 'care home family' passed. Participants related that staff don't always acknowledge when someone dies and consequently may not provide much needed support to residents.

*"When people die here in the home the staff don't really talk too much about it.... No, they don't talk about death here at all you know. I suppose everybody is scared of death, we all are, and they don't really want to hear about it. But death is part of life and important to all of us (Ellen, 5 months).*

*I get especially emotional about people dying in here, like when I see that there's two coffins that have gone past my door. Then I wait for them to come back down again you know.... I get upset when they are taking them to the hospital or wherever they take them... and you see, you start to get used to these things.... going back and forward. I can see that out of the door (Bernadette, 5 months).*

### **3.5 Caring Relationships: 'I didn't realise that I was lonely until I had company'**

Maintaining existing relationships and building new ones- 'I like having the company'

Relationships with family and friends were imperative in determining the quality of life for participants. These relationships enhanced their continued emotional well-being and sense of fulfilment within the care home.

*"Well my family are good to me; they do anything I ask and take me out home to visit and come in here too. But sure, I was living on my own so that wasn't good. I have my family and that at the end of the day that is what is important to me" (Tony, 5 months).*

*"My son never left my side at the beginning; he was always popping in to make sure that I was alright and that I didn't feel lonely here. He still does... I think that he doesn't want me to feel that I am abandoned, and you know what, that really helped me settle" (Tracey, 5 months).*

Participants articulated that fellow residents had the potential to influence their lives positively, encouraging a sense of well-being for themselves and amongst the 'care home family' in general.

*"I am friends with everyone in here. I like having the company. There are a couple of old ladies, well four or five of us that get together in the wee sitting room and chat away. I like that. It's the new sitting room. We go up there on a Tuesday and sit and chat and play music you know" (Anne, 12 months).*

*"I am friendly with George next door; we don't do much together ..... But well we go down to the dining room to have dinner and I always talk to him then. I look forward to that" (Charles, 11 months).*

*"I am getting on great with all the residents and staff. I love it here. They are like a family here; everyone here makes you feel as if you are part of a big family" (Kevin, 5 months).*

Relationships with Staff - 'the staff can make or break the place'

Participants also recognised the significance of supportive and respectful staff who 'made them feel at home' from the outset of the move and on a day-to-day basis.

*"I think the staff are very important. They helped me to feel at home from the beginning. I can tell you, every single day since I have been here, they have been more than good to me" (Anne, 5 months).*

*"Anything you need, well you just go down to the office and they will help you. They also come and remind you what things are going on, so you don't miss out. I would go so far as to say that it is perfect. It's a long time since I was this happy" (Isobel, 12 months).*

*"The staff treat me, what's the word? with respect. Yeah. There's more people that have had bad treatment in care homes but not me" (Kevin, 12 months).*

*"Well you can't fault the staff. I mean they're brilliant. They're all very good to me and they have a great sense of humour.....and they always take time to talk to me" (Sean, 5 months).*

Positive relationships between staff and residents were identified, with most participants describing staff as caring, kind and influential in making them 'feel at home'. However, some participants also perceived that some care staff were authoritative and uncaring. Charles, who is from a military background, had his own unique way of expressing his relationship with staff

*"Some of the staff are like the Gestapo, I wouldn't cross them at all. Others are just great. They would go out of their way to help you and make sure that you are alright, but they are so busy and really, they don't have much time. The manager is very good. You have got to have confidence in the people*

*who care for you. That is important. They need to know what they are doing. I have always said that the staff can make or break a place and that's true" (Charles, 5 months).*

*"Relationships with staff are very important. You either like them or hate them that's the way. There is only one or two of them that you would say to yourself 'I hope I don't get her today' because they don't care about you at all, and that's just the way it is (Laughs). I have to say though that most of the staff are pretty good. They are the most important people" (David, 12 months).*

Participants highlighted the negative emotional impact of losing 'favourite' or 'good' staff when they moved on to other employment. Some participants also spoke about the difficulty in developing relationships with staff due to a high turnover of staff in the care home.

*"The staff definitely make it more homely. Do you know John do you? he is one of the nurses here, Och he's a great fella and gets everybody going. He's just lovely, but he is leaving now, he got another job in a different care home. That's the problem staff are changing all the time, you don't really get to know them as they don't stay that long" (Martha, 12 months).*

*"Usually the staff are quite good here, but I think they're short of staff. Two left at the weekend.... they're going to work in the hospital. I'm wondering if they are paying them better elsewhere, simple as that.....The odd time they will tell you if they are going ....you feel for them... the last chap that left, he was very well liked. We'll miss him because he was very good" (Therese, 12 months).*

#### Companionship and Loneliness 'you are on your own and feel lonely'

Many participants had experienced loneliness prior to moving to the care home and new friendships within the home significantly contributed to their sense of home, quality of life and wellbeing.

*"Life is good now. I have accepted that I am staying here for good. I am happy.... I will not be going anywhere. You know ... I didn't realise that I was lonely until I had company" (Kevin, 12 months).*

However, some participants still experienced loneliness, in particular those who had no family of their own, or individuals who had no shared interests with other residents.

*"I think what makes a big difference when you're living in a care home is if you don't have any family, you are on your own and feel lonely. I mean you can see here at the weekend that nearly everybody gets visitors you know, and I get nobody because I have no family here" (Ellen, 5 months).*

Many participants spoke about getting to know other residents' families and friends when they came to visit and how this enriched their lives also. These interactions contributed to their appreciation of a 'care home family'. One participant recounted losing 'care home family friends' after their relative had died which upset her emotional well-being leading to isolation and loneliness.

*"A man I knew whose wife was upstairs died there recently; it was very sad. The family used to come in to see me too every day at dinner time. I miss them coming in, as I feel lonely some days. I don't really have anyone here to talk to" (Bernadette, 11 months).*

## Discussion

This study set out to explore the experiences of 17 older adults following transition from home to living in a care home with a specific focus on the latter part of the first year of the move. Given the paucity of research concerning the adaption process for older people moving to a care home (Bradshaw et al., 2012; Brownie et al., 2014; Krizaj et al., 2016; Roy et al., 2018), the aim was to discover more about the extent to which older people can be facilitated to feel 'at home' in a care home environment. Five distinct categories captured the experiences between five months and twelve months after the move to a care home. Identified categories were: 1) The lasting effect of first Impressions– 'They helped me make my mind up' 2) On a Journey - 'I just take it one day at a time', 3) Staying connected



and feeling 'at home' - '*You get something good out of it you know...you get hope*'. 4) Managing loss and grief '*It was important for me to say cheerio to the house*' and 5) Caring relationships '*I didn't realise that I was lonely until I had company*'. Together these five categories formed the basis of the core category the 'Primacy of 'Home' which encapsulates the experiences of the participants who placed significance on having a sense of belonging both within the care home and with their continued connections with 'family and home'. These findings concur with international research that has identified how the loss of an individual's home, can compromise identity, belonging, sense of self (Lee et al., 2013; Brownie et al., 2014; Osterlind et al., (2017), well-being and quality of life (Molony 2010; Rioux and Werner 2011; Bokerman et al., 2012). Additionally, the loss of an individuals' previous social and communication networks (Zamanzadeh et al., 2016) can put older people at risk of feeling lonely and isolated (Brownie et al. 2014).

#### *'Primacy of 'Home'*

Establishing a sense of belonging or 'finding home' in a care home involves a process of adjustment (Cooney, 2012; Lindley and Wallace 2015) and has a significant psychological and emotional impact for the individual concerned (Marshall et al., 2008; Cooney 2012; Falk et al., 2013). Moreover, the aptitude to feel at home in care home settings is said to influence residents' perceived quality of life (Tester et al., 2004; Bowers et al., 2009; Hedayati et al., 2014; James et al., 2014). The concept of 'home' is complex, and has been explored from gerontological, environmental, and psychological viewpoints (Moe et al., 2013). Home is not simply a physical space, but it also denotes a meaningful 'place' which embodies physical, personal, and social dimensions (Wahl & Oswald, 2010); extending beyond the household itself to encompass the neighbourhood and wider community (Bigonnesse et al., 2014). Additionally, Lovatt (2018), found that rather than the meaning of home being inherent in objects, or felt subjectively by residents, meaning is generated through ongoing, everyday interactions between the two. She suggests 'that life goes on', and that residents continue to 'do home' by actively turning the spaces of their rooms into places of home through habitual practices and by adding to their material surroundings albeit within a different setting and with more limited capabilities.

Participants spoke about the importance of maintaining connection to their own home, family, friends and community which enabled them to move towards a positive adaptation and acceptance of living in the care home. Even twelve months after the move to the care home, participants identified the positive effect on psychological well-being of getting a visit home and having respite visits from the care home. This is significant as often the focus of family and care home staff is on trying to 'replace' home by creating a 'home from home' environment rather than embracing the importance of an older person maintaining their connections to home, family and community which enhances their continued emotional well-being and sense of fulfilment within the care home. Within this study eleven out of the seventeen participants visited their own home or a relatives' home on a regular basis (1-3 monthly) and three participants undertook activities in the community on a weekly basis. All these participant visits were instigated, planned and participants accompanied by family and friends.

'These findings generally resonate with research undertaken by Cooney (2012) who identified the determinants for 'finding home' as being 'continuity', 'preserving personal identity', 'belonging' and 'being active and working. Cooney informs that the potential to 'find home' is affected by mediating and facilitating/constraining factors. In addition, Rijnaard et al., (2016) found that a sense of home is influenced by psychological factors including preservation of one's habits and values, autonomy and control, coping and social factors, interaction and relationship with staff, residents, family and friends. The importance of maintaining connection to home, family, and community has also been recognised within Paddock et al's., (2018) study when they explored how life in a care home can affect the identity of care homes residents. They found that most residents had little contact with anyone outside of the care home and thus were unable to maintain identity-affirming connections. They advocated that care homes have the potential to accommodate a multitude of identities by facilitating links with previous social networks or symbols that are necessary to maintain a sense of self within the care home.

In this study the 'Primacy of 'Home' is central to residents' positive adaptation to living in a care home, this involves having the right to make choices about their lives and to take risks. Respecting people's basic human rights to dignity, freedom and respect underpin good quality health and social care. The World Health Organisation (WHO) advocate that health care systems should be systematized around older people's preferences and needs, designed to enhance older peoples' intrinsic capacity, and integrated across settings and care providers (WHO, 2015). Moreover, the National Institute for Health and Care Excellence guidelines (2015) advocate that an individual's care plan should include ordinary activities outside the care home to encourage participation in the community, reduce social isolation, and build personal confidence and emotional resilience. This may however present challenges for health care professionals who have a responsibility to ensure residents' safety and may influence their decision-making when accommodating clients' requests for outdoor activity (Mapes, 2017). Furthermore, it is recognised that despite risk being part of health care, nurses may be opposed to taking risks with innovative approaches to care provision due to public or professional criticism should things go wrong (RCN, 2013). It is also recognised however that residents are normally dependent on family and friends to support their engagement with activities outside the care home and without this input they may not leave the care home (Paddock et al., 2018). In essence, care home staff usually do not have the staffing levels to make community connections a reality for residents. Furthermore, care homes are highly regulated environments and nursing and health care staff must follow policy directives, guidelines and recommendations for best practice. That said, there is a need to balance people's human right to make choices by facilitating the needs and preferences of older persons and involving them in decision making. Commissioning bodies have capacity to influence the way care services are organised and delivered and can stipulate specific practice and outcomes aimed at protecting and promoting human rights.

#### *'A sense of belonging'*

For all participants getting settled into 'their new home' was a process that occurred over time and individual responses varied with no set time for familiarisation to begin and end. For some older

people a sense of belonging in their 'new home' was experienced from the outset, and these positive first impressions continued to influence their experiences throughout the first year of the move. Many participants within this study spoke about how their own a personal level of resilience and positive thinking promoted positive adaptation and acceptance experiences to living in the care home. A key factor in participants feeling 'at home' was whether they were involved in the initial decision to move and choice the facility which appeared to permeate their experience of the move thereafter. This finding is also firmly endorsed within the literature (Chao et al., 2008; Johnson et al., 2010; Fraher & Coffey, 2011; Cooney, 2012; Lee et al., 2013; Johnson and Bibbo 2014; Ryan & McKenna 2015; Tanner et al., 2015; O'Neill et al., 2020).

It has been identified that key indicators of residents' acceptance and adjustment to the care home include the ability to establish a sense of home, maintain self-identity and self-worth, and develop positive relationships with peers and staff (Molony, 2010; Cooney, 2012; Falk et al., 2013; Graneheim et al., 2014; Roberts & Bowers, 2015; Shin et al., 2015; Krizaj et al., 2016; Mortenson et al., 2016). Within this study, participants identified the importance of having good relationships with staff and residents with most participants describing staff as caring, kind and influential in making them 'feel at home'. However, some participants also perceived that some care staff were authoritative and uncaring. One participant (Charles) stated, 'the staff can make or break the place'. Furthermore, participants articulated that fellow residents and their families and friends had the potential to influence their lives positively, encouraging a sense of well-being for themselves making them feel at home amongst the 'care home family'. These attributes are reflected within Nolan et al.'s (2006) Senses Framework when considering how positive relationships can be created and sustained. They put forward that in order to have a 'sense of belonging', older people need to have 'opportunities to maintain and/or form meaningful and reciprocal relationships, to feel part of a community or group as desired'.

#### *'Making a good move'*

Some participants in this study expressed positive feelings about living in the care home from the outset of the move. This optimism was fostered by the participant themselves and by hospital and care home staff who promoted and endorsed the positivity of the move for the individual concerned. For other participants, their own a personal level of resilience and positive thinking promoted positive adaptation and acceptance experiences to living in the care home over time. However, it is clear that for some participants in this study the move was not of their choosing, had not turned out the way that they had hoped, or felt 'cheated' that they had not been placed in the type of home or locality they wished to be. These core issues prompted one participant (Ellen) to make plans to leave for Australia and another (Sean) to spend his days longing for home and waiting on a care package that did not materialise, perpetuating his unhappiness. It is evident from the literature that a more successful transition or adjustment to a care home is associated with a planned admission rather than unplanned admission, (Walker and McNamara, 2013; Gilbert et al., 2015; Koppitz et al., 2017). Furthermore, it has been positively endorsed within the literature that a person will perceive their relocation more positively after being introduced to a care home prior to the move (Sury et al., 2013; Graneheim et al.,

2014; Sussman and Dupuis., 2014). There is an important message to be said about collaborating with individuals and their families to identify individual expectations post move to the care home. Some perhaps difficult and caring conversations need to take place prior to and during the move about future care needs, as not identifying or disregarding people's views and opinions can create a poor adaptation (Bradshaw et al., 2012; Brownie et al., 2014; Krizaj et al., 2016).

*'Psychological and emotional well-being'.*

Within this study the 'Primacy of 'Home' is identified as the importance of residents making and maintaining 'connections' thus promoting their mental health and well-being. Core to understanding how a positive adaptation can be made is recognising the significance of the need for a continuing relationship and continuing connection with home, family and community. Residents need and want something to look forward to, either in terms of getting out for a while with family; or family coming in to visit and spend time; and the opportunity to form relationships with other residents and care workers. It is recognised that loneliness and isolation are key issues associated with admission to long term care (Cooney, 2012; Sury et al., 2013; Brownie et al., 2014; Krizaj et al., 2016; Hanratty et al., 2018). Conversely, many participants in this study experienced loneliness prior to moving to the care home and friendships developed thereafter significantly contributed to their 'sense of home', quality of life and emotional wellbeing. However, some participants still experienced loneliness up to a year after the move, particularly those who had no family of their own, or individuals who had no shared interests with other residents. Moreover, those participants who felt that they 'had no choice' about the move or choice of care home were still reporting feelings of sadness, regret and lowered mood (Thein et al., 2011; Brownie et al., 2014; Bowers et al., 2015). Grief is a normal process of reacting to a physical loss, such as a death, or a social loss including a relationship. Bereavement is the period after a loss during which grief and mourning occur. The time spent in bereavement for the loss of a loved one depends on the circumstances of the loss and the level of attachment to the person who died (Casarett et al., 2001). It is noted that a higher prevalence of complicated grief is indicated in the age range of 75 to 85 years (Newson et al., 2011), denoting more difficulty coping with a loss. Research indicates that older people go through multiple losses of family and friends within their lifetime (Shear et al., 2013) with the transition to widowhood considered the most stressful adjustment to make in later life (Silverstein and Giarrusso, 2010). Moreover, many older people experience bereavement, loss of home and loss of physical function when they move to a care home and also when other residents die within the home (Reed et al., 2002). Within this study some participants were also grieving loss of family members and others were trying to cope with loss associated with ageing, loss of home and loss of independence. These findings resonate with literature that suggests numerous losses including bereavement are common in old age and present emotional, physical and practical challenges (Nicholson et al., 2012; Shear et al., 2013; Ebrahimi et al., 2015; van Humbeeck et al., 2016). Some participants identified how they were positively supported by social workers and care home staff to control how and when they said goodbye to their house when they were 'letting go of home' and how this enabled a successful adaptation to their 'new home'. In

contrast, not all participants had existing social supports to cope with bereavement and loss in the care home. This study suggests that the grief and loss experienced by participants when family, friends or a member of 'care home family' dies is not always understood by staff.

The findings from this study clearly identify that older people's experiences of care transition vary, in terms of their support needs and their adaptation to the care home. Our study has identified that individuals' perceptions of the 'Primacy of 'Home' is connected to their perceived quality of life, continued connection to home, family and community, having opportunities to develop meaningful relationships promoting a sense of belonging amongst their 'care home family'. The aptitude to feel at home includes control, autonomy, and supportive staff relationships and is endorsed within the literature, (Bowers et al., 2009; Cooney, 2012; Bradshaw et al., 2012; Brandburg et al., 2013; James et al., 2014; Ericson-Lidman et al., 2015; Krizaj et al., 2016). This study is significant because the data was collected up to a year after moving to the care home and there is limited research that has explored the experiences and perspectives of older people up to this time period.

### Conclusion

In this study the 'Primacy of 'Home' is identified as a place where participants feel valued, nurtured and have a sense of belonging. Older people living in care homes should not be seen as a homogeneous group with a single set of requirements. Moreover, it is very important that older people are enabled to realise their individuality, ability and potential, should that be within the care home or by having continued connection to family and community. Managing individual preferences and expectations from the outset can enable older people to move towards acceptance rather than disabling them which leads to disillusionment and unhappiness. First impressions are very important and have been shown within this study to influence participants' experiences throughout the first year of the move leading to a more positive adaptation journey. Key recommendations from this study include the need to raise awareness of the significance of the ongoing psychological and emotional well-being needs of older people which should be considered in policy directives and clinical practice. This could include identifying initial and ongoing expectations for each resident as opposed to service provision facilitated by a senior member of the care home staff with overall responsibility for working in partnership with individuals and families. A designated person should be identified to support and facilitate the psychological and emotional needs of the older person going through bereavement and loss. In addition, individuals and families need to be facilitated and supported to have continued honest and caring conversations to promote acceptance and adaptation to living in a care home while continuing to embrace the heart of home. Initiatives such as My Home Life, an international programme that aims to promote quality of life and positive change in care homes, offers leadership support to provide managers with the knowledge and skills to inspire and lead culture change in care homes (Penney and Ryan, 2018). My Home Life ([www.myhomelife.co.uk](http://www.myhomelife.co.uk)) advocates that 'best practice together' can be developed by focusing on relationships and having meaningful dialogue and interaction with older people and families. The Caring Conversations Framework (Dewar & Nolan, 2013) enhances this engagement and interaction. The framework suggests that, in order to deliver compassionate and dignified care, people need to Be Courageous (giving things a go), Celebrate

(finding what worked well), Connect Emotionally (finding out how it made the person feel), Be Curious (understanding what is happening), Collaborate (working together), Consider Other Perspectives (what do others think?), and Compromise (what is real and possible?). It also supports a different attitude to risk-taking and devising new approaches to problems. In everyday practice, providing quality care relies on care home staff applying their values, attitudes, knowledge and skills. Care home managers are central to this process and with support, can bring about the culture change required to create the sort of 'home like' environment highlighted by participants in this study.

#### References:

- Bigonnesse, C., Beaulieu, M., Garon, S. (2014). Meaning of Home in Later Life as a Concept to Understand Older Adults' Housing Needs: Results from the 7 Age-Friendly Cities Pilot Project in Québec. *Journal of Housing for the Elderly*, 28, 357-382. 10.1080/02763893.2014.930367.
- Böckerman, P., Johansson, E. and Saarni, S.I. (2012) Institutionalisation and subjective wellbeing for old-age individuals: is life really miserable in care homes? *Ageing and Society*, 32(07), 1176-1192.
- Bowers H., Clark A., Crosby G., Easterbrook L., Macadam A., MacDonald R., Macfarlane A., Maclean M., Patel M., Runnicles D., Oshinaike T. & Smith C. (2009) Older People's Vision for Long-Term Care. York: Joseph Rowntree Foundation. Available at: <http://www.jrf.org.uk/sites/files/jrf/older-people-vision-for-care-full.pdf>
- Bowers, B., Nolet, K., Jacobson, N., THRIVE Research Collaborative (2015). Sustaining Culture Change: Experiences in the Green House Model. *Health services research*, 51 Suppl 1(Suppl 1), 398-417.
- Bradshaw, S., Playford, E. and Riazi, A. (2012). Living well in care homes: a systematic review of qualitative studies. *Age and Ageing*, 41(4), pp.429-440.
- Brandburg, G., Symes, L., Mastel-Smith, B., Hersch, G. and Walsh, T. (2013) Resident strategies for making a life in a nursing home: a qualitative study. *Journal of Advanced Nursing*, 69(4), 862-874.
- Brownie, S., Horstmannshof, L., and Garbutt, R. (2014) Factors that impact residents' transition and psychological adjustment to long-term aged care: A systematic literature review. *International Journal of Nursing Studies*, 51(12), pp.1654-1666.
- Cassarett, D., Kutner, JS. and Abraham, J. (2001) Life after death: a practical approach to grief and bereavement. In: Snyder L, Quill T, eds. *Physician's Guide to End of Life Care*. Philadelphia: American College of Physicians:178–93.
- Chao, S.Y., Lan, Y.H., Tso, H.C., Chung, C.M., Neim, Y.M. and Clark, M.J. (2008) Predictors of psychosocial adaptation among elderly residents in long-term care settings. *Journal of Nursing Research*, 16(2), 149-158.
- Cooney, A. (2012) 'Finding home': A grounded theory on how older people 'find home' in Long-term care settings. *International Journal of Older People Nursing*, 7(3), 188-199.
- Corbin J. and Strauss A. (2008) *Basics of Qualitative Research*, 3rd edn. Sage, Thousand Oaks, California.
- Crawford, K., Digby, R., Bloomer, M., Tan, H. and Williams, A. (2015) 'Transitioning from caregiver to visitor in a long-term care facility: the experience of caregivers of people with dementia', *Ageing & Mental Health*, 19 ( 8), 739– 46.
- Dewar, B., Nolan, M. (2013). Caring about caring developing a model to implement compassionate relationship centred care in an older people care setting. *Int. J. Nurs. Stud.* 50 (9), 1247–1258

- Dewing J (2009) Making it work: a model for research and development in care homes, in Froggatt K, Davies S, Meyer J (eds) *Understanding Care Homes: A Research and Development Perspective*, Jessica Kingsley Publishers, London, pp. 222–241.
- Ebrahimi Z., Dahlin-Ivanoff S., Eklund K., Jakobsson A. & Wilhelmson K. (2015) Self-rated health and health-strengthening factors in community-living frail older people. *Journal of Advanced Nursing* 71(4), 825–836. doi:10.1111/jan.12579
- Ericson-Lidman, E., Larsson, L.L., and Norberg, A. (2014) Caring for people with dementia disease (DD) and working in a private not-for-profit residential care facility for people with DD. *Scand J Caring Sci.* 28: 337–346
- Falk, H., Wijk, H., Persson, L. and Falk, K. (2013) A sense of home in residential care. *Scandinavian Journal of Caring Sciences*, 27(4), 999-1009.
- Fitzpatrick, J. M., & Tzouvara, V. (2019). Facilitators and inhibitors of transition for older people who have relocated to a long-term care facility: A systematic review. *Health & Social Care in the Community*, 27(3), e57–e81. <https://doi.org/10.1111/hsc.12647>
- Fraher, A. and Coffey, A. (2011). Older people's experiences of relocation to long-term care. *Nursing Older People*, 23(10), 23-27.
- Gilbert, S., Amella, E., Edlund, B., & Nemeth, L. (2015). Making the Move: A Mixed Research Integrative Review. *Healthcare (Basel, Switzerland)*, 3(3), 757-74. doi: 10.3390/healthcare3030757
- Graneheim, U.H., Johansson, A., & Lindgren, B. (2014) Family caregivers' experiences of relinquishing the care of a person with dementia to a nursing home: Insights from a meta-ethnographic study. *Scandinavian Journal of Caring Sciences*, 28 (2), 215-224.
- Grant, J., Brutscher, P.B, Kirk, S. Butler, L. and Wooding, S. (2009) *Capturing Research Impacts: A review of international practice* Cambridge: RAND Europe
- Hanratty, B., Stow, D., Collingridge, D., Moore, N., Valtorta, K., Matthews, F. (2018). Loneliness as a risk factor for care home admission in the English Longitudinal Study of Ageing, *Age and Ageing*, Volume 47, Issue 6, Pages 896–900, <https://doi.org/10.1093/ageing/afy095>
- Hedayati, M.A.M., & Khazaei, M. (2014) An Investigation of the Relationship between Depression, Meaning in life and Adult Hope *Procedia - Social and Behavioral Sciences*, 114(21), 598-601.
- James I, Blomberg K, and Kihlgren 2014. A meaningful daily life in nursing homes - a place of shelter and a space of freedom: a participatory appreciative action reflection study. *BMC Nursing*: 13:19.
- Johnson, R. and Bibbo, J. (2014) Relocation decisions and constructing the meaning of home: A phenomenological study of the transition into a nursing home. *Journal of Aging Studies*, 30(1), 56-63.
- Johnson, R., Popejoy, L., & Radina, M. (2010) Older adult's participation in nursing home placement decisions. *Clinical Nursing Research*, 19(4), 358-375.
- Katz J. Holland C. Peace S., & Taylor E. (2011). A better life: What older people with high support needs value. Retrieved from Joseph Rowntree Foundation: [www.jrf.org.uk/publications/older-people-high-support-needs.full.pdf](http://www.jrf.org.uk/publications/older-people-high-support-needs.full.pdf)
- Koppitz, A., Dreizler, J., Altherr, J., Bosshard, G., Naef, R., and Imhof, L. (2017) Relocation experiences with unplanned admission to a nursing home: a qualitative study. *International Psychogeriatrics*, 29(3), 517-527.
- Križaj, T., Warren, A. and Slade, A. (2018) "Holding on to What I Do": Experiences of Older Slovenians Moving into a Care Home. *The Gerontologist*, Volume 58, Issue 3, June 2018, Pages 512–520, <https://doi.org/10.1093/geront/gnw150>
- Lee, V., Simpson, J and Froggart, K. (2013). A narrative exploration of older peoples transitions into residential care. *Aging and Mental Health*, 17(1), 48-56



- Lincoln, Y. And Guba, E. (1985) *Naturalistic Enquiry*. California; Sage Publications.
- Lindley, S., & Wallace, J. (2015). Placing in Age: Transitioning to a New Home in Later Life. *ACM Transactions on Computer-Human Interaction (TOCHI)*, 22(4), 20.
- Lovatt, M. (2018) Becoming at home in residential care for older people: a material culture perspective, *Sociology of Health & Illness*, 40, 2, 366–78.
- Mapes, N. (2017). Think outside: Positive risk-taking with people living with dementia. *Working with Older People: Community Care Policy & Practice*, 21(3), 157–166
- Marshall, E., Mackenzie, L. (2008) Adjustment to residential care: the experience of newly admitted residents to hostel accommodation in Australia. *Aust. Occup. Ther. J.*: 55:123–132
- Maz, J. (2013). Employing grounded theory approach: Core characteristics. *British Journal of Cardiac Nursing*, 8(9), 453-458.
- Meleis, A. I. (2010). *Transitions Theory—middle range and situation specific theories in nursing research and practice*. New York: Springer Publishing Company.
- Moe, A., Hellzen, O., Enmarker, I. (2013) "The meaning of receiving help from home nursing care," *Nursing Ethics*, vol.20, no. 7, pp. 737–747.
- Molony, S.L. (2010) The meaning of home: A qualitative metasynthesis. *Research in Gerontological Nursing*, 3(4), 291-307.
- Morse, J. M. (2009). Exploring transitions. *Qualitative Health Research*, 19, 431
- Mortenson, B. W., Sixsmith, A., Beringer, R. (2016). No place like home? Surveillance and what home means in old age\*. *Canadian Journal on Aging*, 35(1), 103-114. doi:10.1017/S0714980815000549
- Newson, R.S., Boelen, PA, Hek K, Hofman, A. and Tiemeier, H. (2011). The prevalence and characteristics of complicated grief in older adults. *Journal of Affective Disorders* 2011;132(2): 231–8. doi:10.1016/j.jad.2011.02.021.
- National Institute for Health and Care Excellence (NICE). (2015) Transition between inpatient hospital settings and community or care home settings for adults with social care needs (NG27). Available at: <https://www.nice.org.uk/guidance/ng27/chapter/Recommendations#discharge-from-hospital>. [Accessed 20.06.20].
- Nicholson C., Meyer J., Flatley M., Holman C. & Lowton K. (2012) Living on the margin: understanding the experience of living and dying with frailty in old age. *Social Science and Medicine* 75(8), 1426– 1432. doi: 10.1016/j.socscimed.2012.06.011
- Nolan, M., Brown, J., Davies, S., Nolan, J., & Keady, J. (2006). *The SENSES framework: Improving care for older people through a relationship-centred approach*. University of Sheffield. ISBN 1-902411-44-7.
- NVivo qualitative data analysis Software; QSR International Pty Ltd. Version 12, 2018.
- Nwe, W.T., D'Souza, G. and Sheehan, B. (2011) Expectations and experience of moving to a care home: Perceptions of older people with dementia. *Dementia* (14713012), 10 (1), 7-18.
- O'Neill, M., Ryan, A., Tracey, A., & Laird, LEA. (2020). "You're at their mercy": Older peoples' experiences of moving from home to a care home: A grounded theory study. *International Journal of Older People Nursing*, [e12305]. <https://doi.org/10.1111/opn.12305>
- Österlind J, Ternestedt B-M, Hansebo G, Hellström I. (2017) Feeling lonely in an unfamiliar place: older people's experiences of life close to death in nursing home. *Int J Older People Nursing*. <https://doi.org/10.1111/opn.12129>.
- Paddock K, Brown Wilson C, Walshe CE and Todd C (2019) Care home life and identity: A qualitative case study. *The Gerontologist* 59, 655-664. doi.org/10.1093/geront/gny090



- Penney, S. and Ryan, A. (2018) The effect of a leadership support programme on care home managers. *Nursing Older People*. 30(1), 35-40. <https://doi:10.7748/nop.2018.e979>
- Perry, T., Andersen, T., Kaplan, D. (2013). Relocation Remembered: Perspectives on Senior Transitions in the Living Environment. *The Gerontologist*. 54. 10.1093/geront/gnt070.
- Pritty, B., De Boos, D. and Moghaddam, N. (2019) 'Factors influencing the transition experience of carers for persons with dementia, when the person with dementia moves into residential care: systematic review and meta-synthesis', *Aging & Mental Health*, 12, 1– 10
- Reed, J., Cook, G. and Burridge, C., (2002). 'Loss and change.' In: Hockley, J. and Clark, D., 2002. *Facing Death: Palliative Care for Older People in Care Homes*. Buckingham: Open University Press
- Royal College of Nursing (2013) RCN Congress and Exhibition Liverpool 21-25 April 2013. Agenda Item 25: A risk worth taking? Older People's Forum. London: Royal College of Nursing
- Rijnaard, M. D., van Hoof, J., Janssen, B. M., Verbeek, H., Pocornie, W., Eijkelenboom, A., Beerens, H. C., Molony, S. L., & Wouters, E. J. (2016). The Factors Influencing the Sense of Home in Nursing Homes: A Systematic Review from the Perspective of Residents. *Journal of aging research*, 2016, 6143645. <https://doi.org/10.1155/2016/6143645>
- Rioux, L. and Werner, C. (2011) Residential satisfaction among aging people living in place. *Journal of Environmental Psychology*, 31(2), 158-169.
- Roberts, T. and Bowers, B. (2015) How nursing home residents develop relationships with peers and staff: A grounded theory study. *Int J Nurs Stud*, 52: 57–67
- Roy, N., Dubé, R., Després, C., Freitas, A., & Légaré, F. (2018). Choosing between staying at home or moving: A systematic review of factors influencing housing decisions among frail older adults. *PloS one*, 13(1), e0189266. <https://doi.org/10.1371/journal.pone.0189266>
- Ryan, A. and McKenna, H. (2015) it's the little things that count'. Families experience of roles, relationships and quality of care in nursing homes. *International Journal of Older People Nursing*, 10, 38-47. DOI: 1111/opn.12052.
- Shear, M. K., Ghesquiere, A., & Glickman, K. (2013). Bereavement and complicated grief. *Current psychiatry reports*, 15(11), 406. <https://doi.org/10.1007/s11920-013-0406-z>
- Shin J.H. & Hyun T.K. (2015) Nurse staffing and quality of care of nursing home residents in Korea. *Journal of Nursing Scholarship* 47 (6), 555– 564
- Silverstein, M. and Giarrusso, R. (2010). Aging and family life: a decade review. *Journal of Marriage and Family*. 72:1039–58
- Strauss, A. and Corbin, J. (1990) *Basics of Qualitative Research* (1st Edn.). Thousand Oaks: CA: Sage.
- Strauss, A. and Corbin, J. (1998) *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* (2nd Ed.). Thousand Oaks: London
- Sury, L., Burns, K. and Brodaty, H. (2013) Moving in: adjustment of people living with dementia going into a nursing home and their families. *International Psychogeriatrics*, 25(6), 867-876
- Sussman, T. and Dupuis, S. (2014) Supporting Residents Moving Into Long-Term Care: Multiple Layers Shape Residents' Experiences. *Journal of Gerontological Social Work*, 57 (5), 438-459.
- Tanner, D., Glasby, J., McIver, S. (2015). Understanding and improving older people's experiences of service transitions: Implications for social work. *British Journal of Social Work*, 45(7), 2056–2071. doi:10.1093/bjsw/bcu095
- Tester, S., Hubbard, G., Downs, M., MacDonald, C., & Murphy, J. (2004). What does quality of life mean for frail residents? *Nursing and Residential Care*, 6, 89–92. doi:10.12968/nrec.2004.6.2.12052

Thein, N. W., D'Souza, G. and Sheehan, B. (2011). Expectations and experience of moving to a care home: perceptions of older people with dementia. *Dementia*, 10, 7–18.

Tsai HH, Tsai YF. (2008) A temporary home to nurture health: lived experiences of older nursing home residents in Taiwan. *Journal of clinical nursing*.17(14):1915-22.

Van Humbeeck, L., Dillen, L., Piers, R., & Van Den Noortgate, N. (2016). Grief and loss in older people residing in nursing homes: (un)detected by nurses and care assistants? *Journal of Advanced Nursing*, 72(12), 3125–3136.

Wadensten B., Conden E., Wahlund L. & Murray K. (2007) How nursing home staff deal with residents who talk about death. *International Journal of Older People Nursing* 2(4), 241–249.doi:10.1111/j.1748-3743.2007.00095.x

Walker, E. and McNamara, B. 2013. Relocating to Retirement Living: An Occupational Perspective on Successful Transitions. *Australian Occupational Therapy Journal*, 60, 445-453.

Wahl HW, Oswald F. (2010) Environmental perspectives on ageing. In: Dannefer D, Phillipson C, editors. *The Handbook of Social Gerontology*. London, UK: Sage; pp. 111–124.

Westin L, Danielson E (2007) Encounters in Swedish nursing homes: a hermeneutic study of residents' experiences *J. Adv. Nurs.*, 60 (2) (2007), pp. 172-180

Wiles J.L., Leibling A., Guberman N., Reeve J. & Allen R. (2012) The meaning of "ageing in place" to older people. *The Gerontologist* 52 (3), 357– 366

Zamanzadeh, V., Rahmani, A., Pakpour, V., Chenoweth, L.L. and Mohammadi, E. (2016) Psychosocial changes following transition to an aged care home: qualitative findings from Iran. *International Journal of Older People Nursing*, 1-10

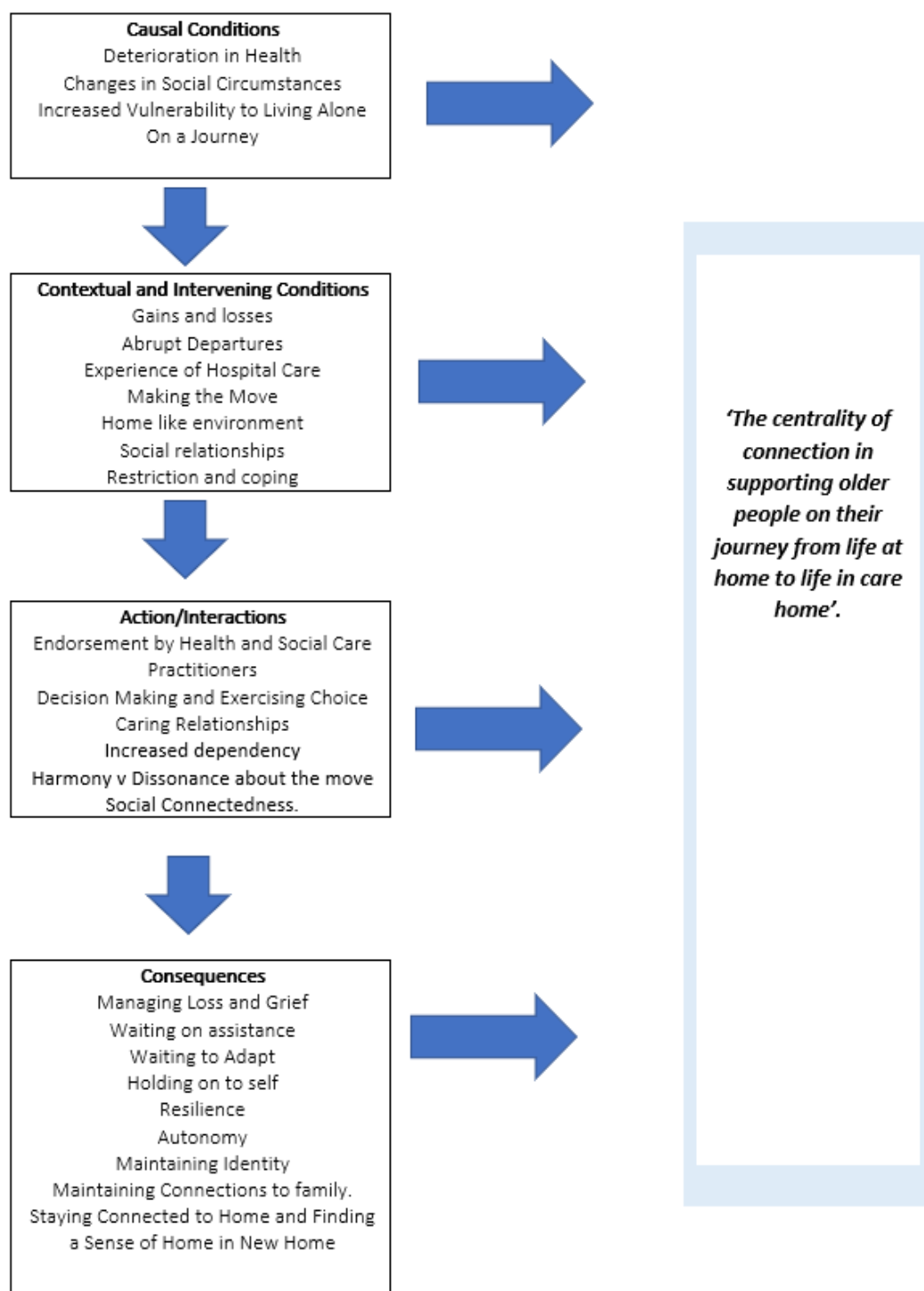
Zizzo, G, Mackenzie, C, Irizarry, C, Goodwin-Smith, I. Loss and grief: The experience of transition to residential aged care. *Aust J Soc Issues*. 2020; 00: 1– 18. doi: 10.1002/ajs4.105.

#### **4.17 The Paradigm Model incorporating the first year of the move**

This section outlines the paradigm model that captures the experiences of older people during the first year of the move to life in a care home. The interconnected aspects of the paradigm model have been discussed within the findings and identified papers. The contextual and causal conditions for individuals making the move to the care home were set in motion by the events relating to their admission. These intervening conditions are linked to experiences of the specific circumstances of the move as evidenced within actions/interactions. Feeling disconnected and dependent on health care professionals, through lack of decision-making and choice are linked to the core category and demonstrate the perceived dependence and ‘at the mercy’ experiences of individuals in the study. Actions and interactions result in consequences which directly influenced individuals’ reactions or non-reactions. The consequences at the time of the move were as a result of the actions/interactions creating a perceived disconnection of self, causing emotional disturbance and personal loss. Individuals were feeling anxious and trying to stay connected to their own identity and home during the move. Thereafter, participants found the weeks following entry to a care home unsettling, and a ‘sense of belonging’ was taking time to develop. They were trying to establish connections to their new home while re-establishing connections to their home and family. Within this context, most individuals identified that adapting to life in a care home was an ongoing process that they were mainly trying to navigate themselves with little support from care home staff or others. Individuals identified restrictive practices, increased dependency, and lack of autonomy as barriers to adaptation and developing a sense of home. In addition, concepts within the consequences category underpin the core category as individuals wanted to maintain connections to their own identity, sense of self, family, and home, while ‘finding

home' and developing connections within their new environment. See Paradigm Model Figure 4.7 below.

**Figure 4.7:** *Participants experience of the first year of moving from home to a care home: Relationship of major categories to each other and to the core category*



#### 4.18 Bringing it all together: David's Journey

The findings presented thus far tell the story about how life in a care home was experienced by participants at different timepoints in the first year of the move. For some participants, a sense of belonging in their 'new home' was experienced from the outset but for others it took time to develop if at all. Before moving on to present the core category that draws all the findings from these time points together under an overarching core category, the reader is introduced to David (pseudonym) who tells his own personal story and in doing so illustrates the centrality of connections in supporting older people along their journey to life in a care home. David is 88 years old and lived alone prior to admission to hospital following a fall at home. At the first interview, David explained that he was waiting to be transferred to the care home. He described how lonely he felt living at home and how he missed feeling connected to his wife who lived in a care home.

*My health was always very good, but suddenly I thought things were not right. My wife had depression and then she went to XXXX and I was in the house alone and kind of lonely. The children came often. I took sick myself, they couldn't find the cause of it, it seemed to be a kind of nervous reaction to everything, but it took a long time to try and get a diagnosis. I'm too old to be on my own now. I chose the nursing home for my wife. She has been there for a year now, I liked what I saw.*

David also spoke about how the care home manager and hospital staff were the key people making the decisions and organising the move to the care home stating:

*When the bed becomes available well that's it, apparently you have to grab it. The sad thing for me about moving to the care home tomorrow is that I'm walking in a dead man's shoes!*

At the second interview five weeks later in the care home, David was less enamoured with the move. Although he had chosen the care home for his wife and visited her there several times weekly prior to the move, the care home had not quite met his expectations. David talked about not feeling connected to either the staff or other residents within the home reporting:

*Of course, my wife was here already. She settled down quickly, but I'm not really settled yet. I want to go back home. I know I didn't expect to settle quickly, but it's taking a bit longer than I thought it would.*

With further discussion it was evident that David found the care home restrictions a threat to his independence and autonomy. He spoke at length about care home routines and imposed rules of having to wait for assistance “to do anything, even visit my wife” as being a big frustration to him.

*Although I have a Zimmer frame, I still have to have someone to take me anywhere, I'm not allowed to walk on my own, but I think I'm fit to walk on my own. I feel restricted I think that's my main problem. If I want to go to the toilet, I have to call somebody. And they know rightly that I could do it but that's the rules and I have to obey them. You have to get used to the waiting. And of course, you realise that if you ask for something there may be three other people who have asked before you. So, you have to have patience.*

David still felt disconnected at the five month interview and expressed a desire to get out of the “atmosphere” even for a while. He still had hopes of returning home, David said he could live independently if house adaptations were undertaken and a stair lift

served. At this point David had still not made any connections to others in the home and for most of the time felt isolated. He perceived that his independence was restricted which had an impact on his emotional well-being.

*It's no different here, I would love to just to get out of this atmosphere. There are a lot of deaths here. I still have hope of getting home, and I think if they would do something about my hands I would be away and could manage on my own with a bit of home help and then worry about everything else after I get home. I think that there are too many rules and regulations here, your life is not your own and you are not allowed to move about without having to ask for permission*

David had a more optimistic outlook at the twelve month interview. He talked about the importance of the relationships that he had developed with both residents and care staff. David felt these connections had a positive influence on his outlook and daily life within the care home. In terms of relationships with residents David said:

*there is this kind of invisible bond between us and we like to know how everyone is getting on. Some you get on with some you don't, just the same as ordinary life.*

David also spoke about the importance of having a good relationship with care home staff:

*Relationships with staff are very important. You either like them or hate them that's the way. There is only one or two of them that you would say to yourself, I hope I don't get her today because they don't care about you at all, and that's just the way it is (Laughs). I have to say though, that most of the staff are pretty good. They are the most important people.*

It was significant that at the twelve month interview, David started making connections with others when he was ‘allowed’ to ‘mobilise independently’ and restrictions had been lifted. That is, he was allowed out to garden on his own and visit his wife when he wanted to. Interestingly, field notes confirmed that on every single visit to the care home during that year David was observed sitting on his own at the front door of the care home. This was the case until the twelve month interview when he was sitting amongst other residents and it seemed that “a sense of belonging” had developed. It was evident that David had become much more content to live in the care home when he gained independent mobility stating:

*I have got my independence back again. The sanctions have been lifted. I don't think that I will ever be home again now. It has come naturally to me..... It just takes time to come to that realisation.....Things are better now.*

#### **4.19 The Substantive Theory**

The substantive theory that emerged from this study recognises the unique experience of each individual's move to a care home and also the common experiences that participants shared. At the beginning, the majority of participants felt that the move was out of their control and ‘*You're at their Mercy*’ of others who made decisions about their long-term care. Key factors influencing the move were the individuals' perceived lack of autonomy, choice and decision making in planning and making the move. The second phase of the transition experience related to the initial adaptation experiences of the men and women in the study who were ‘*Waiting and Wanting*’ to reconnect with their family, friends, home, and community. Individuals were trying to make sense of the process of adaptation, while trying to take control of their lives

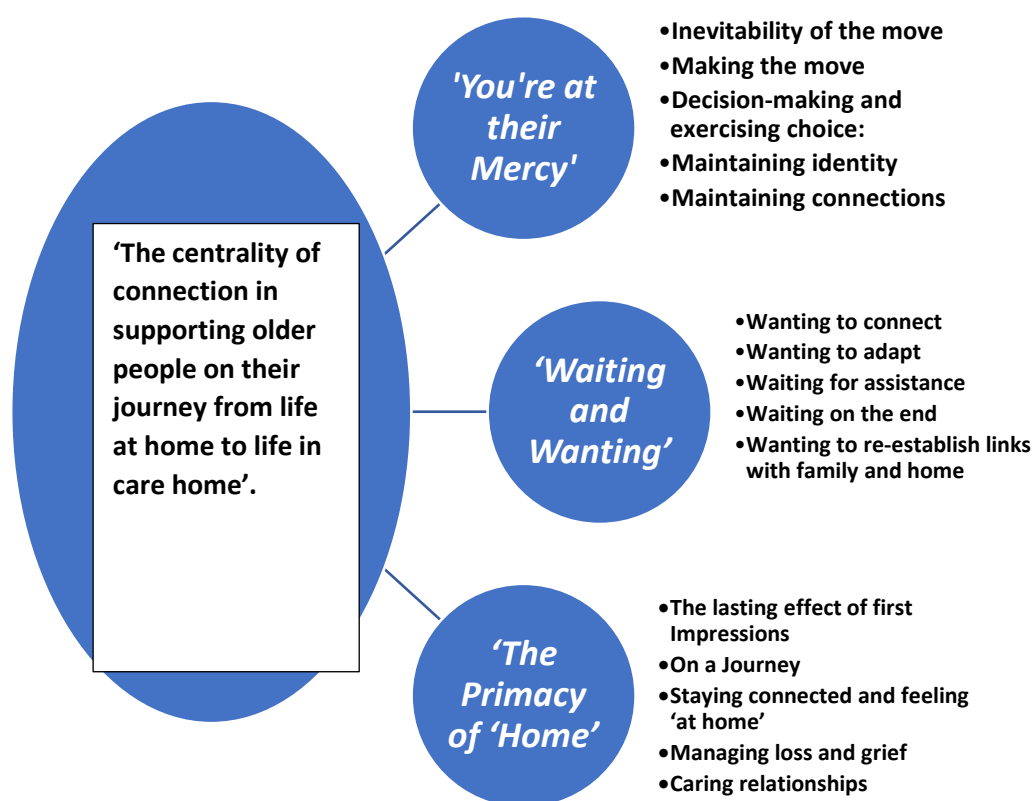


and avoid dependence. The third and final phase of the transition journey involved participants' experiences and perceptions of '*The Primacy of 'Home'*'. Individuals identified the care home as a place where they would like to feel valued and nurtured. Participants emphasised the importance of maintaining their identity and having a sense of belonging both within the care home and with their continued connections with 'family and home'. The story line for the first year of the transition to a care home is captured in an overarching category that espouses the '*The centrality of connection in supporting older people on their journey from life at home to life in a care home*'. For example, before and immediately after the move, older people needed to be connected to the decision-making process and to stay connected to their identity. However, this was a challenge and individuals felt 'at the mercy' of family and health and social care staff (disconnection). At four to six weeks post move participants were 'waiting and wanting' to connect and to adapt to life in their new environment. Once the [move](#) became permanent after 4-6 months the importance of connection shifted to incorporate the significance of meaningful connections with care home staff and other residents (establishing new connections) while also re-establishing links with family and home (reconnection).

At the end of the first year, the focus was on maintaining connections and on the importance of the co-existence of connections with the old (previous home, community and family) and the new (new home in the care home and new care home family). Residents who were able to maintain parallel connection with the 'old' and the 'new' appeared to adapt more positively to life in a care home. '*The Primacy of 'Home'*' reflects the primacy of feeling at home regardless of whether it was their former home or their 'home now' in the care homes. The theory that emerged from

this grounded theory study suggests that care home residents who are connected, as evidenced by their participation in decision making about the move and the extent to which they can maintain existing connections to home and family while at the same time, creating new connections within the care home environment, have a more successful transition to life in a care home than individuals who do not have this connectedness. See Figure 4.8 Emergence of Theory

**Figure 4.8:** *Emergence of Theory*



## 4.20 Chapter Summary

This chapter focused on the research findings from the four interview timepoints. Findings from the first interview which was undertaken either pre-move or immediately post-move to the care home suggested that the move and transition to a care home was perceived by individuals to be out of their control. Participants were

‘at the mercy’ of others making the decisions and deciding their future including family members, social workers, community care managers and care home staff. Findings from the second interview at four to six weeks after the move identified that the majority of individuals were ‘Waiting and Wanting’ to connect with others and ‘self’ and make sense of the adjustment. Within this context, most individuals identified that adapting to life in a care home was an ongoing process that they were mainly trying to navigate themselves with little support from care home staff or others. The third and fourth interviews which took place at five to twelve months after the move were analysed together and identified ‘*The Primacy of ‘Home’*’ as a place where participants would like to feel valued, nurtured and have a sense of belonging. It was recognised that facilitating individual preferences and expectations from the outset can empower people to progress towards acceptance rather than impeding them which leads to disillusionment and unhappiness. First impressions were very important and were shown within this study to influence individuals’ experiences throughout the first year of the move leading to a more confident adaptation journey. The story line for the first year of the transition to a care home was captured in an overarching category ‘*The centrality of connection in supporting older people on their journey from life at home to life in care home*’. The theory that emerged from this grounded theory study suggests that care home residents who are connected, as evidenced by their participation in decision making about the move and the extent to which they can maintain existing connections to home and family while at the same time, creating new connections within the care home environment, have a more successful transition to life in a care home than individuals who do not have this connection. The next chapter will provide a detailed discussion about the study findings in light of other relevant research.

## CHAPTER FIVE:

### DISCUSSION

#### 5.1 Introduction

The previous chapter focused on the research findings from four interview timepoints. The story line for the first year of the transition to a care home was captured in an overarching category '*The centrality of connection in supporting older people on their journey from life at home to life in a care home*'. This chapter will discuss how the key findings from the study relate to existing literature. It will also highlight the originality of the study's findings and their unique contribution to knowledge. While major aspects of the study findings are embedded in the published papers included in this thesis, this chapter will further develop the discussion by considering these key aspects in more detail. The chapter begins with an overview of key findings at each interview timepoint, before discussing and synthesising them sequentially and collectively.

The aim of this research study was to explore older people's experiences' of moving from home to a care home over four time points during the first year of the move. The broad research objectives were:

- To explore participants' perceptions of the circumstances surrounding the decision to move to a care home.
- To explore the factors influencing participants' experiences of the first year of their transition to life in a care home.

- To develop a substantive theory contributing to our understanding of the factors supporting a better transition from living at home to living in a care home.

## 5.2 Summary of Key Findings

### **Key Finding One: Time Point One (pre-move (7 days) or post-move (within 3 days))**

**‘You’re at their Mercy’:** Participants perceived a sense of disempowerment being ‘at the mercy’ of their family and health care professionals throughout the admission process. A lack of opportunity and encouragement to participate in decision making, resulted in participants demonstrating a resigned acceptance to their fate and feeling ‘at the mercy’ of others to maintain independence and connections to their own identity, sense of self, family and home.

### **Key Finding Two: Time Point Two (four and six weeks post-move)**

**‘Waiting and Wanting’:** Participants experienced an unsettling period and were disillusioned by a loss of independence, autonomy, and continuity of former roles. They were waiting to reconnect with home and community and to establish connections within their new home. Adaptation was an ongoing process that individuals were trying to navigate themselves, with little or no support.

**Key Finding Three: Time Points Three and Four (Five to twelve months post-move)**

**‘The Primacy of ‘Home’:** Participants placed substantial meaning on preserving their identity and finding connections both within the care home and with ‘family and home’. This enabled them to ‘make it work’ and move towards a positive adaptation and acceptance of living in the care home.

**Key Finding Four: The Substantive Theory**

***‘The centrality of connection in supporting older people on their journey from life at home to life in a care home’:*** The emergent theory identifies that individuals who are supported to maintain pre-move routines and connections to home and family while at the same time, creating new connections within the care home environment, have a more successful transition to life in a care home than individuals who do not have this this connectedness.

### **5.3 ‘You’re at their Mercy’**

Internationally, moving to a care home has been identified as a stressful event in the lives of older adults (Ellis 2010; Brandburg *et al.* 2013; Ryan and McKenna 2015), especially when they are not part of the decision-making process (Thein *et al.* 2011; Brownie *et al.* 2014). Disregard for people’s views can initiate maladaptation to new social circumstances (Bradshaw *et al.* 2012; Brownie *et al.* 2014; Krizaj *et al.* 2018). In this study, participants perceived the admission process to be out of their control. They felt ‘*at the mercy*’ of family members, social workers, community care managers

and care home staff, who they perceived were making decisions on their behalf. Furthermore, there was a strong sense of disempowerment that pervaded these early transitional experiences and in the absence of opportunities or encouragement to make decisions and choices, a resigned acceptance to their fate materialised. The findings at this timepoint are important because the data is collected in the pre-relocation period and there are limited studies undertaken at this crucial time. Two qualitative studies (Reed and Payton 1997; Krizaj *et al.* 2018) are noteworthy exceptions as they explored the experiences and perspectives of older people prior to the move to a care home. However, despite their research participants being interviewed at this stage, neither of these studies reported any details on the pre-move experience, focussing more on the experiences of ‘settling in’. This current study in contrast ascertained rich data that illuminated a disempowering pre move experience, with older people perceiving that decision making was out of their control.

The international literature describes moving to a care home as a traumatic and life-changing experience (Brandburg *et al.* 2013; Sury *et al.* 2013; Ryan and McKenna 2015; McCarthy 2016). However, in this study, the life changing significance of moving to a care home did not appear to be acknowledged or supported by formal services (Cooney 2012; Thein *et al.* 2011; Brownie *et al.* 2014). Consequentially, older people were denied an active role in decision-making and choice, which adversely affected their transition experiences. This finding concurs with the findings of other international studies (Dossa *et al.* 2012; Fuji *et al.* 2012; Hanratty *et al.* 2012; Toles *et al.* 2012).

It is evident from the literature that a more positive transition to a care home is associated with an arranged admission as opposed to unplanned admission (Gilbert *et al.* 2015; Walker and McNamara 2013). In this study, the majority of participants had very little choice in choosing the care home in which they were to spend the remainder of their days. Another challenge which left participants at the ‘*mercy of others*’ was the speed at which the move occurred with the consequence that they had little or no opportunity to consider which possessions they would have liked to bring into the home. This was an important finding as it has been recognised that having and arranging one’s personal possessions and mementos in the care home brings a sense of ‘home’ to the environment, and is a crucial part of successfully adapting to new surroundings (Marshall and McKenzie 2008; Cooney 2012; Falk *et al.* 2012). A rushed, if not chaotic, move to the care home is contrary to internationally respected guidelines (Social Care Institute for Excellence [SCIE], 2020) and research evidence. Sussman and Dupuis (2014) have highlighted that the hallmarks of a planned care home admission are the active involvement of the older person across three stages: the decision to move, pre-move preparation and moving day circumstances.

In keeping with the international research in this field, this study’s findings suggest that the lack of involvement in decision making and choice about the move resulted in a negative experience causing emotional reactions and a perceived sense of personal loss (Fraher and Coffey 2011; Johnson *et al.* 2010; Lee *et al.* 2013; Zamanzadeh *et al.* 2016). It is accepted that having an unexpected or crisis admission can leave participants feeling ‘lost’ and isolated, causing anxiety in their new environment (Koopitz *et al.* 2017). Moreover, participants within this study experienced a lack of autonomy relocating to a care home, and this occurred despite



the international evidence (Cooney 2012; Thein *et al.* 2011; Brownie *et al.* 2014, McKenna and Staniforth 2017) that highlights the importance of preserving a persons' autonomy and value.

There is evidence to suggest that an individual will perceive their transition more confidently if they have a sense of familiarity with a care home prior to the move (Sury *et al.* 2013; Graneheim *et al.* 2014; Sussman and Dupuis, 2014). In a grounded theory study Ryan and McKenna (2013) explored rural family carers' (n=29) experiences of the nursing home placement of an older relative. The theory that emerged indicated that familiarity was the key influence on rural family carers' experiences of their relative's relocation. Findings indicated that those carers who described a significant degree of familiarity seemed to experience a more positive transition. This familiarity was influenced by the large amount of social capital that participants had accrued in their rural communities. Consequently, this familiarity, instigated the nursing home selection and family carers' responses. It is noteworthy that in this current study, very few participants (n=3) had any sense of familiarity with the care home and this may have contributed to their delayed adaptation to life in the care home. However, this does not explain David's experience of struggling with the move, even though he was very familiar with his care home given that he had chosen it for his wife, who also resided there.

It is disconcerting that the majority of participants in this study had a negative experience of moving to a care home. One explanation may be a health and social care system 'under pressure' leading to disempowerment and depersonalisation. Additionally, it is possible that ageist attitudes prevail among health and social care

professionals. Such attitudes may perpetuate passivity on the part of older people and explain their sense of being ‘left out’ of the decision-making process about all aspects of the move.

Being on the receiving end of ageism should not be an inevitable consequence of growing old. The Royal Society for Public Health (RSPH) (2018) have published a report investigating how attitudes to ageing can affect health and wellbeing. The findings indicated that ageist views are held through the generations. Several people considered an ageing society as a challenge instead of an opportunity. A number of recommendations were made to address some of the negative outcomes and key drivers of societal ageism which included the call for healthcare professionals to be trained on the effects of ageism in clinical and care settings and an independent review of the representation of older people in the media. Stereotypical views of older people being ‘frail, dependent, ill and incompetent’ are often confirmed within health care contexts as people may be ill or in dependent situations. This is possibly why healthcare professionals’ acceptance and internalisation of negative attitudes towards old age is reinforced (Swift *et al.* 2017).

Several research studies have focused on ageist attitudes among health care providers including Liu *et al.* (2015), who identified negative, neutral, and positive attitudes about ageing amongst nurses. Similarly, ageism is embedded in the professional culture of nurses in their preference to work with younger patients (Kagan and Melendez-Torres 2015). In 2015, the World Health Organisation approved the first global strategy action plan on ageing and health. The programme directs a change in societal attitudes, more accessible environments, and revisions of health care systems

to align with older people's needs. In doing so, the programme has the potential to address ageism in all aspects of health care delivery.

#### **5.4 'Waiting and Wanting'**

Within this study, the early weeks of transition following the move to the care home were viewed by many individuals as unsettling. In this period, they were enduring losses in independence, autonomy, decision-making, meaningful engagement, interpersonal relationships, and connections to home. Moreover, the loss of an individual's home life posed a significant challenge threatening identity, belonging and sense of self (Lee *et al.* 2013; Brownie *et al.* 2014; Paddock *et al.* 2018), and for many a sense of connection in their new surroundings was taking time to develop (Lindley and Wallace 2015). Individuals were undoubtedly '*wanting*' to connect with others in the care home environment, whilst '*also wanting*' to re-establish links with their family, home, and community. Several studies have determined that leaving home and feeling disconnected from family and communities intensifies feelings of loss and isolation (Iwasiw *et al.* 1996; Lee 1999; Bland 2005; Heliker and Scholler-Jaquis 2006; Saunders and Heliker 2008; Fraher and Coffey 2011; Hutchinson *et al.* 2011). Adapting to a care home's 'rules and regulations' and '*waiting*' for assistance were significant causes of frustration for individuals in this study. The requirement to 'learn the ropes' has also been identified as creating stress and anxiety for some individuals (Wilson 1997; Lee 2001; Heliker and Scholler-Jaquis 2006).

Various concerns, including health and social issues can influence the adjustment and adaptation journey for older people after relocating to a care home (Bradshaw *et al.* 2012; Brownie *et al.* 2014; Krizaj *et al.* 2018). Within this study, some individuals

experienced emotional responses in their early weeks of living in the care home stating *“I am getting to the stage that I don’t want to go on”, “I am so lost here, it’s not me, it’s not home and it’s so big, I don’t really know where I am at now. It is very hard to find your way”*. Similar experiences in the early transition stages of relocating to a care home have previously been identified by Bridges’ (2004). Furthermore, Bridges purports the early transition stage as encompassing an ending; a period of confusion which can bring about high anxiety levels; and a new beginning. Within this study, the individuals whose relocation experience was deemed to be positive, expressed hopeful affirmations *“Well I always take it one day at a time and thank God it’s been good so far”*, and *“Oh, I love it here I really do”*. The findings in this time period resonate with the first two stages of Brandburg’s (2007) transition process framework to the extent that the initial responses to the move were marked by emotional reactions, and in the second stage, it was the individual’s personal characteristics, values, and history, and the background to the admission that appeared to be influencing whether the relocation experience was being viewed as positive or negative. Within this context, most individuals in these initial weeks identified that their adaptation to life in a care home was a process that they were trying to navigate themselves with minimal support from care home staff or others. Thus, the early adaptation phase of settling into life in a care home was an anxiety provoking experience.

Meleis’s theory of transitions describes how a person relates to their health and environment and how a change in either can alter how a person perceives his/her role. Moreover, Meleis (2010) explains that an individual’s reaction to change can be affected by internal (attitude, knowledge, cultural beliefs) and external factors (social

support, socioeconomic status). At this timepoint, some individuals expressed their frustration at ‘*Waiting for assistance*’ from care home staff to help with personal care needs while trying to retain their own ‘identity’ and independence. They expressed frustration, annoyance and resentment that care home staff were impeding their personal strives towards independence, by carrying out activities that new residents could undertake for themselves. Such actions were perceived to be restrictive and were construed as reducing their autonomy. These experiences resonate with the findings of Paddock *et al.* (2018), who suggested that institutional restrictions, standardised routines, and strict risk management policies can impede individuals’ autonomy and independence. It has been acknowledged that when individuals are not afforded their independence, they can feel undermined, become depressed and even doubt their ability to look after themselves (Wiersma and Dupuis 2010; Custers *et al.* 2012). Low expectations of staff can become a self-fulfilling prophecy as residents’ level of engagement in previously honed activities is reduced, as evidenced by a decline in overall health and cognitive ability (Chin and Quine 2012; Lee *et al.* 2013; Zamanzadeh *et al.* 2016). In the gravest case-scenario, losing independence can bring about losing the will to live, as expressed within the quote ‘*When you are this old you understand that life must come to an end. I have no family, you know. I would like to die now and be free from all difficulties [the pain and the way of feeling of being treated in the nursing home]*’ (Osterlind *et al.* 2017: p. 4).

Research has identified that after moving to a care home, individuals can lose interpersonal connections and find it difficult to create new relationships (Zamanzadeh *et al.* 2016), and thus they run the risk of being lonely and isolated (Brownie *et al.* 2014). Additionally, it is recognised that care home staff have a vital

role to play in supporting new residents to develop social connections within the home (Cooney 2012; Krizaj *et al.* 2018). Conversely, Eika *et al.* (2014) identified a lack of awareness among care home staff about the emotional impact that moving to a care home can have on the person. In the initial weeks post transition, all the participants recognised the importance of '*Wanting*' to re-establish connections with their family and home. This involved maintaining interpersonal connections with family members and friends, in addition to developing new relationships with staff (Saunders and Heliker 2008; Lee 2010; Brandburg *et al.* 2013; Falk *et al.* 2012; Sussman and Dupuis 2014; Ryan and McKenna 2015). A few participants who were '*Wanting to connect*' with other individuals in the home, identified having trouble in making connections with other residents; citing frailty as an impeding factor (Lee *et al.* 2013). In addition, developing social connections with staff was perceived both positively '*they are like a family and treat you like one of their own*' and less favourably "*Some of the nurses are nice. But if you need help, they aren't in a hurry. I am getting to know who to ask now*". This latter quote is illustrative of less meaningful relationships (Eika *et al.* 2014).

While some participant accounts depict a negative attitude towards care staff within the home, it is very important to acknowledge examples of good practice and delivery of person-centred care. There is potential for care home staff to play a significant role in creating a welcoming 'home' environment and this must be recognised and appreciated. This study's findings reinforce the need for active and on-going commitment to the recruitment and retention of innovative caring staff who want to champion care for older people. Such measures are crucial to altering the public perception of care homes and care home staff.

The importance of developing relationships within the care home is also considered within the systematic review of Fitzpatrick and Tzouvara (2018). The authors associated possible facilitators and inhibitors that corresponded with Meleis's (2010) personal and community transition conditions, and in particular, within the theme of interpersonal connections and relationships for older people. These connections centre on family, care home staff, other residents, and significant others beyond the care home. Likewise, when considering how relationships can be developed, nurtured, and sustained, Nolan *et al.*'s (2006) 'Senses Framework' identified six senses that are considered prerequisites within the context of care and service provision. The six senses are a: Sense of security: *To feel safe*; Sense of belonging: *To feel part of things*; Sense of continuity: *To experience links and connection*; Sense of purpose: *To have a personally valuable goal(s) to aspire to*; Sense of achievement: *To make progress towards these goals*; and Sense of significance: *To feel that 'you' matter as a person*. In essence, the Senses Framework is an acknowledgement of the importance of each person in a relationship having a sense of significance and feeling that they matter as a person, and in application, that good care can only be delivered when the six 'senses' are experienced by all the groups concerned.

The findings from this study undeniably recognise that for the vast majority of participants the first four to six-week period following the move to a care home was unsettling, and for some, it was a distressing experience. This timepoint for data collection was again significant because there is minimal research that has investigated the experiences of older people during these early weeks post move. In previous research, Iwasiw *et al.* (1996) classified residents' experiences after

admission to a care home into four categories: emotional reactions, transition activities, reflecting on their situation and connecting with a personal philosophy. Iwasiw et al. surmised that a more positive experience was related to the level of involvement in planning the move, the meanings that residents attached to the experience and their emotional state; concordant with this study's findings. Heliker and Scholler-Jaquish (2006) identified three patterns and themes in the transition to nursing home living which were identified as: (1) becoming homeless, (2) getting settled and learning the ropes, becoming known and knowing others and learning the rules, and (3) creating a place and making the best of it. The researchers inferred that if staff had knowledge of how residents grieve for loss of home, whilst acknowledging that the transition is an unfamiliar and unknown experience, it could lead to an anticipation of an individual's specific needs, and innovative practice change. How the concept of home emerges during transition to a care home has also been explored in a phenomenological study undertaken by Johnson and Bibbo (2014). Interviews were conducted with eight older adults at two weeks and two months post the move to a care home. Findings suggested that while participants still retained strong connections to home, their attitudes changed between the first and second interviews, with the difference explained as being related to the level of perceived autonomy in older adults' definitions of home.

In this study actively maintaining continuity between the individual's past and present role was a significant factor in the process of a positive adaptation and this finding has not been identified within other studies at this stage of transition. Participants categorically affirmed their desire and need to keep connections to home, family, and community alive. Moreover, from the outset they wanted to lead full and purposeful



lives, and to realise their ability and potential within the care home and avoid dependence on others. Significantly, during this early phase of transition, care home staff were predominantly perceived as providers of care and not as persons with whom residents could connect with and develop relationships. In Andersson *et al.*'s (2005) study describing older peoples' experiences after admission to a care home, it was surmised that residents were generally satisfied with their daily life. A standout area of contrast in their study when compared to this study, was that all of the participants except one had participated in the decision to move to the care home. This study identified that only four out of twenty-three participants were involved in making the decision to move into a care home. The relocation experiences reflected in a more recent study conducted by Fraher and Coffey (2011) were similar to this study, with findings that conveyed that decisions about moving to long term care are poorly handled, with lack of choice and personal involvement. Fraher and Coffey found that people accepted and adjusted to their new situation more quickly when the admission was planned. This study's findings are also substantiated by Sussman and Dupuis (2014) who sought to find out what conditions helped or hindered older adults towards a more positive experience of the relocation process. They determined that if a self-initiated decision was made pre-move, then this enhanced residents' sense of control and self. The authors concluded that proactive decisions increased the opportunities for residents to experience positive relocations.

### **5.5 'The Primacy Of 'Home'**

The literature conveys that the loss of an individual's home, can compromise identity, connectedness, sense of self (Lee *et al.* 2013. Brownie *et al.* 2014; Osterlind *et al.* 2017), well-being and quality of life (Molony 2010; Rioux and Werner 2011;

Bokerman *et al.* 2012). Additionally, the loss of an individual's previous social connectedness (Zamanzadeh *et al.* 2016) can put older people at risk of feeling lonely and isolated (Brownie *et al.* 2014). Between the five and twelve months' time period after the move to the care home, the participants in this study perceived '*The Primacy of 'Home'*' to be associated with their stated quality of life. '*The Primacy of 'Home'*' embraced a continued connection to home, family and community, while having opportunities to develop meaningful relationships and a sense of connectedness with their 'care home family'. The aptitude to feel at home, including having control and autonomy, and developing supportive relationships with staff, are findings that are endorsed within international research literature (Bowers *et al.* 2009; Cooney 2012; Bradshaw *et al.* 2012; Brandburg *et al.* 2013; James *et al.* 2014; Ericson-Lidman *et al.* 2015; Krizaj *et al.* 2018). It is important to recognise that making the transition to a care home can present additional difficulties to some groups of older people, such as those with dementia, older people from black and minority ethnic communities, and those with complex and multiple needs (Ellins *et al.* 2012; Khan, 2015).

This study has identified that establishing a sense of belonging or 'finding home' in a care home involves a process of adjustment (Cooney 2012; Lindley and Wallace 2015) and has a major psychological and emotional impact for the individual concerned (Marshall *et al.* 2008; Cooney 2012; Falk *et al.* 2012). Moreover, the ability to feel at home in a care home has an effect on each person's perceived quality of life (Tester *et al.* 2004; Bowers *et al.* 2009; Hedayati *et al.* 2014; James *et al.* 2014). This is evident within a more recent grounded theory study undertaken in Lebanon by Adra *et al.* (2017) that explored quality of life in two nursing homes with a theoretical sample of twenty residents, eight family caregivers and eleven home staff. The

findings demonstrate how quality of life is a complex phenomenon and that, in the care process, recognising how the distinct role of “maintaining self, identity and continuity” is crucial to enhancing the quality of life of nursing home residents.

The concept of ‘home’ is complex, and has been investigated from gerontological, environmental, and psychological viewpoints (Moe *et al.* 2013). Home is not just a physical space, but also signifies a meaningful ‘place’ which includes physical, personal, and social dimensions (Wahl and Oswald 2010); including the wider community (Bigonnesse *et al.* 2014). Equally, Lovatt (2018), observed that rather than the meaning of home being intrinsic within objects, or experienced subjectively by residents, meaning is created through ongoing, ordinary interactions concerning the two. She suggests ‘that life goes on’, and that residents continue to ‘do home’ by actively changing their rooms into ‘home’ via routine practices and by enhancing their material surroundings albeit within an altered setting and with more restricted capabilities.

Within this study, participants were very clear about the substantial value they placed on maintaining connections to their previous life, home, family, and community which empowered them to move towards a more positive adaptation and acceptance of living in the care home. It was significant that one year after the move to the care home, participants identified the positive effect of getting a trip home and respite visits away from the care home, on their psychological well-being. This is noteworthy as quite often the focus of family and care home staff is to try to ‘substitute’ home by creating the concept of ‘home from home’ instead of accepting that an older person wants to retain their connections to their former home, their family and community

since this enriches their continued emotional well-being and sense of fulfilment within the care home. These important findings resonate with research undertaken by Cooney (2012) who recognised that ‘continuity’, ‘preserving personal identity’, ‘belonging’ and ‘being active and working’ made it simpler or more problematic for older people to ‘find home’ in long term care environments. Also, Rijnaard *et al.* (2016) found that a sense of home is influenced by psychological factors including safeguarding one's habits and values, autonomy and control, coping and social factors, all of which are bolstered by interaction and relationships with staff, residents, family and friends.

For all the participants in this study, getting settled into ‘their new home’ was an evolving process and individual responses differed with no set period identified for familiarisation to start and finish. For a minority of the participants a sense of connectedness to their ‘new home’ was felt from the outset, and these positive first impressions were sustained throughout the first year of the move. Many participants within this study expressed how their own personal level of resilience and optimism encouraged positive adaptation and acceptance to residing in the care home. This study confirms that a key factor in participants feeling ‘at home’ was whether they are included in the decision to move and in making the choice about which care home to relocate to. The level of inclusion in the decision-making process seemed to permeate their experience of the move thereafter. This finding is strongly endorsed within the literature (Chao *et al.* 2008; Johnson *et al.* 2010; Fraher and Coffey 2011; Cooney 2012; Lee *et al.* 2013; Johnson and Bibbo 2014; Ryan and McKenna 2015; Tanner *et al.* 2015).

In this study, participants strived to maintain their identity by preserving past and present interpersonal connections and relationships to facilitate ‘adjustment’ and come to terms with the move. These findings correlate to Brandburg’s (2007) second and third stages of the transition process, as in transitional influences (personal and care home characteristics), and the adjustment experience (maintaining previous relationships and developing new ones, and reflecting on their new home), interact and interplay throughout the process of transition. The importance of maintaining connections to home, family, and community has also been identified within Paddock *et al.*’s (2018) study exploring the effects of care home life on residents’ identity. Findings indicated that most residents had hardly any communication with anyone outside of the care home, thereby rendering it difficult to maintain identity-affirming connections.

It has been recognised within the literature that crucial indicators of an individual’s adjustment and acceptance to a care home incorporates the capacity to establish a sense of home, maintain self-identity and self-worth, and create positive interpersonal connections with residents and care staff (Molony 2010; Cooney 2012; Falk *et al.* 2012; Graneheim *et al.* 2014; Roberts and Bowers 2015; Shin *et al.* 2015; Mortenson *et al.* 2016; Krizaj *et al.* 2018 ). In this study, the attitudes of some of the participants towards care staff changed at this timepoint, as they acknowledged the value of making and sustaining new social connections. Most participants described staff as caring, kind, and influential in enabling them to ‘feel at home’. Nonetheless, some participants also felt that some care staff were authoritative and uncaring. These qualities are reflected within Nolan *et al.*’s (2006, p.34) Senses Framework when considering how positive relationships can be developed and sustained. They suggest

that in order to have a 'sense of belonging', older people need to have 'opportunities to maintain and/or form meaningful and reciprocal relationships, in order to feel part of a community or group as desired'.

*'The Primacy of 'Home'* emerged as the core category recognising the significant value individuals placed on maintaining connections with home and making 'connections' in their 'new' home, thus supporting their mental health and well-being. Central to knowing how a positive adaptation can be made is recognising the importance of continuing connections with home, family, and community. It has been identified that maintaining continuity between the individual's past and present role is an important factor in the adaptation journey following the move to a care home (Bradshaw *et al.* 2012; Brownie *et al.* 2014; Krizaj *et al.* 2018). In this study *'The Primacy of 'Home'* emphasises the significant influence of connectedness to home and family in promoting an individual's positive mental health and well-being. It is accepted that isolation and loneliness are core issues associated with admission to long term care (Cooney 2012; Sury *et al.* 2013; Brownie *et al.* 2014; Hanratty *et al.* 2018; Krizaj *et al.* 2018). Equally, many participants in this study experienced loneliness prior to moving to the care home and the friendships they developed thereafter notably influenced their 'connectedness', quality of life and emotional wellbeing. Conversely, some participants were lonely up to a year after the move, particularly individuals who did not have any connections with family, or those who perceived that they had no mutual interests with other residents. Likewise, participants who believed they 'had no choice' about moving to a care home or choice of care home were still describing feelings of sadness, regret and lowered mood, and this is recognised within the international literature (Thein *et al.* 2011; Brownie *et al.* 2014; Bowers *et al.* 2015).

Research indicates that older people go through multiple losses of family and friends within their lifetime (Shear *et al.* 2013). Additionally, many older people experience bereavement, including loss of home and physical function when they relocate to a care home as well as when other residents die within the home (Reed *et al.* 2002).

Within this study, some participants were grieving the recent loss of family members and others were trying to manage losses associated with ageing, the loss of home, and loss of independence. These findings resonate with literature that advises how frequent losses including bereavement are familiar in old age and pose emotional, physical, and practical challenges for the older person (Nicholson *et al.* 2012; Shear *et al.* 2013; Ebrahimi *et al.* 2015; van Humbeeck *et al.* 2016). A small number of participants in this study indicated how they were positively supported by social workers and care home staff to manage how and when they wanted to say goodbye to their house and ‘disconnect with home’. The assistance and support received may have promoted a successful adaptation to their ‘new home’. However, not all participants had existing social support connections to support them when trying to cope with bereavement and loss. This study suggests that the grief and loss experienced by participants when family, friends, or a member of ‘care home family’ dies is not always understood or recognised by care home staff.

The findings presented at this timepoint (up to a year after the move to a care home) are original and represent a unique contribution to knowledge as there is limited research that has explored the experiences and perspectives of older people throughout this time period. A similar study undertaken by Iwasiw *et al.* (2003) found that the majority of residents appraised the long term care facility negatively, particularly after

three months whereas in this study when continued connections to home were established, and past and present relationships maintained and developed, most participants took a more positive view of living in the care home. Comparably, and as previously stated personal and social identity were investigated within a multiple qualitative case study undertaken by Paddock *et al.* (2018). Findings indicated that impacts of aging that were already influencing a reshaping of residents' identities were exacerbated by the care home environment. A significant finding of this study was that care home restrictive practices threatened autonomy and independence, causing residents to redefine this within care home rules. Furthermore, stringent routines and resource limits resulted in the bounded expression of their personalities. Both Iwasiw *et al.* (2003) and Paddock *et al.* (2018) have also conveyed the importance of maintaining identity, personhood, and social comparison. However, this study identified the significance of actively reconnecting with family, home, and community outside of the care home environment from the outset of the move, thus maintaining a sense of personhood. Furthermore, this study has also surmised that individuals' perceptions of '*The Primacy of 'Home'*' are connected to their perceived quality of life, continued connection to home, family and community, having ongoing connections to their past home life and people, while still having opportunities to develop new and meaningful relationships; all of which are promoting a sense of belonging in their present home and amongst their 'care home family'.

## **5.6 The centrality of connections**

The importance of participants making and maintaining 'connections' has been recognised in this study which identified '*The centrality of connection in supporting older people on their journey from life at home to life in care home*' as the core and



umbrella category that draws on the findings from the four time points together. The centrality of connections identifies the need to support individuals when determining the management of the move to a care home while maintaining connections to their home throughout the transition. In this study a lack of decision making, disconnectedness with home and family and dependence on health care professionals were linked to a more negative adaptation journey. It is recognised that the transition to a care home offers many challenges including the loss of the individual's home, identity, and connectedness to others (Lee *et al.* 2013; Brownie *et al.* 2014; Fitzpatrick *et al.* 2018; Paddock *et al.* 2018). In this study individuals were trying to establish connections to their new home while re-establishing connections to their home and family but did not feel supported during this process. While it has been recognised that a positive adaptation to a care home includes the ability to create a sense of home, maintain self-identity, and foster positive relationships with residents and staff (Cooney 2012; Falk *et al.* 2012; Graneheim *et al.* 2014; Krizaj *et al.* 2018); the significance of maintaining connections to home and community have not been established within the literature. The core category espoused in the 'centrality of connections' is an important contribution to research evidence as frequently care home staff and family try to create a 'home from home' whereas, it may be the case that many individuals would rather keep their connections to their former home and home life, family and community, to bolster their sense of self and identity, and effect a more positive adaptation journey. This study's findings suggest changing the portrayal of life in a care home. It is evident that the challenge is not to try and replace an individuals' connections with 'home' but rather support a parallel focus of maintaining existing connections to their former home life and family while creating new connections within the care home.

## **5.7 Chapter Summary**

This chapter has presented an analytical discussion of how the key findings from the study relate to existing literature. It has also highlighted the originality of the study's findings and its unique contribution to knowledge. In the next and final chapter of this thesis, conclusions and recommendations are made for research and practice.

## CHAPTER SIX:

### CONCLUSIONS AND RECOMMENDATIONS

#### 6.1 Introduction

The previous chapter presented an in-depth discussion about the study findings in light of existing literature. This chapter will begin by summarising the key conclusions, recognising the study's unique contribution to knowledge, and identifying its limitations. Consideration of how the findings have the potential to influence future policy, practice, and education will be made. The chapter concludes with a reflection of my PhD journey and recommendations for future research.

#### 6.2 Conclusion

Globally, it is predicted that the need for health and social care delivery will increase due to population ageing which will have a significant impact on the necessity for care home provision into the future. However, despite the plethora of studies taking place in care homes, there is a paucity of research on older people's experiences of the move from a longitudinal perspective. This study addressed this issue with its focus on individuals' experiences of the move during the first year of living in a care home. Study findings give voice to all of the older people who have powerfully articulated their experiences at four key critical time points during their transition.

The story line for the first year of the transition to a care home was captured in an overarching category '*The centrality of connection in supporting older people on their journey from life at home to life in a care home*'. The theory that emerged from this grounded theory study suggests that care home residents who are connected, as

evidenced by their participation in decision making about the move and the extent to which they can maintain existing connections to home and family while at the same time, creating new connections within the care home environment, have a more successful transition to life in a care home than individuals who do not have this connectedness.

This study increases understanding about how older people make a positive adaptation to living in a care home. In this study, participants were forthright about how getting a visit home and having respite visits away from the care home had a beneficial effect on their psychological well-being. This is a significant finding as frequently care home staff and family try to 'replace' home by creating another 'home from home' environment as opposed to accepting that an individual may wish to maintain their connections to home, family and community which consequently enriches their sense of fulfilment and level of contentment within the care home.

This study identified that the majority of participants experienced a lack of autonomy in the management of their move to a care home. This lack of autonomy created a negative experience causing emotional disturbance and personal loss leading to individuals feeling anxious and dependent on others during the move. This study augments the current body of evidence which recognises the lack of service provision for older people making the move, signifying a health care failure to tackle older peoples' health and social care needs during the transition to life in a care home. Furthermore, findings also suggest that pressures on acute and primary care services are resulting in a failure to meet the needs of older people during this critical life transition which in turn leads to disempowerment and depersonalisation of the person.

The current processes of pre-move assessment, care home admission and ongoing support for older people is inadequate. Despite the emotional and stressful outcomes for older people during this major life event, these issues have not been addressed and have resulted in continued negative experiences for this population group. It is imperative that health care providers recognise that older people need to be active participants in all decisions about their care needs. It is by facilitating difficult and caring conversations with individuals and their families along with managing individual expectations from the outset of the move, that a positive adaptation may begin to take place.

It could also be argued that the management of the move was inherently ageist as the significance of such a major life event and its impact on older people did not receive the attention and support given to other population groups undergoing significant life transitions, e.g. young people starting school, university, new employees having access to induction programmes etc. The importance of bringing a sense of home and possessions into the care home was also identified as having a significant impact on individual's emotional well-being. It is vital that due consideration is given to the psychological needs of individuals moving to a care home who are undergoing complex changes and losses affecting their emotional well-being and identity. Health care professionals have a key role to play in collaborating with older people around decision-making, planning and moving to a care home. More emphasis could be placed on facilitating autonomy and choice so that older people do not feel 'at the mercy' of others as they navigate this major transition.

In the early weeks following the move, participants felt dependent on others to develop a sense of connectedness with others and ‘self’ and to maintain independence and well-being. Within this context, most individuals were trying to adjust and adapt to their new life with minimal support from care staff or others and this provoked further anxiety. During this period, participants saw care home staff largely as care providers and not as people with whom to develop social connections.

Consistent with international literature, risk averse practices were perceived as a threat to an individual’s independence and autonomy (Wiersma and Dupuis 2010; Thein *et al.* 2011; Custers *et al.* 2012; Brownie *et al.* 2014; Paddock *et al.* 2018). These findings suggest that it is imperative from the outset of a transition to a care home, to acknowledge and respect individuality in such a way as to recognise and act on a person’s values and preferences in terms of physical and psychological safety and promoting independence. It is also important that care home staff understand, as many in this study did, that they do not need to try and ‘substitute’ an individual’s home but instead recognise that maintaining connections to home, family and community can enhance emotional well-being and provide a sense of fulfilment which can help people feel more at home.

‘The Primacy of ‘Home’ was identified as a place where participants would like to feel valued, nurtured and have a sense of belonging. It was recognised that facilitating individual preferences and expectations from the outset can empower people to progress towards acceptance rather than impeding them which leads to disillusionment and unhappiness. First impressions were very important and were shown within this study to influence individuals’ experiences throughout the first year

of the move leading to a more confident adaptation journey and acceptance of living in the care home. It is essential that older people are not seen as a uniform group with similar requirements and that individuality is maintained while living in care homes. Managing individual preferences and expectations from the outset can enable older people to move towards acceptance earlier which can lead to a more positive adaptation journey. Care home staff and relatives have the potential to maintain and support the identity of individual residents by supporting the continuation of existing interpersonal connections and relationships and establishing new social connections. This endorses the National Institute for Health and Care Excellence guidelines (2015) which advocate that an individual's care plan includes undertaking ordinary activities outside the home to encourage participation in the community, reduce social isolation, and build personal confidence and emotional resilience. It is through connections with family and friends, and community engagement that wellbeing is enhanced to create '*The Primacy of 'Home'*' where individuals would like to feel valued, nurtured and have a sense of belonging as conveyed by participants in this study.

### **6.3 Recommendations for Policy**

#### **Care Transitions**

The Service Framework for Older People (DHSSPS 2013) and 'The Enhanced Health in Care Homes Framework' (NHS England 2016), set standards in relation to person-centred care including transitions of care and obtaining a holistic picture of a person's preferences and goals that have not been evidenced within this study. Findings indicate that there is a need to increase health care professionals' understanding of the importance of making a transition to a care home from the perspective of older people making the move and revise policy and practice accordingly. This may involve having

a personalised induction programme for each new resident facilitated by a community care manager and senior member of the care home staff responsible for collaborating with the individual, their families and the wider health and social care team. Furthermore, there is a need for policy directives to contain auditable guidelines to ensure equal access to health, social care, and rehabilitation services after moving to a care home. The findings of this study also have implications for the management and inspection of care homes. Quality of care needs to value and investigate the degree to which older people truly feel 'at home' as evidenced by their level of decision making, autonomy and choice during transition and in everyday activities.

#### Recruitment and selection of staff

Global ageing and the expectation of a growing demand for long-term care needs to be addressed in the context of continued public negativity of quality of care home provision. There is a long-standing concern about the recruitment and retention of care home staff. It is very important that care home staff are valued for the meaningful work that they do by providing adequate support, training, and better remuneration as this may reduce turnover and lead to a more stable workforce. In addition, recruitment should include the ability to demonstrate personal commitment and values to work within this specialised area.



## **6.4 Recommendations for Practice**

### Decision-making and management of the move

It is important that health care professionals are able to collaborate and work in partnership with older people to support and enable them to make decisions and plans about their future health and social care needs including the possibility of living in a care home when they are unable to manage their own needs. These discussions should not be deferred until the older person becomes acutely ill but become part of a regular health assessment with a G.P, keyworker, or district nurse.

Healthcare professionals have an important part to play working alongside older people concerning decision-making and management of the move to a care home. A strong emphasis on autonomy and choice is advocated so that older people are supported to manage such an important transition, and this could be documented and reviewed as needed.

### Maintaining independence

A person's individuality needs to be recognised, and values and preferences accepted in terms of promoting independence while maintaining their physical and psychological safety. A culture of maintaining independence and maximising rehabilitation needs to be fostered by all health care staff taking due cognisance of direction and recommendations from relevant health care professionals to facilitate a more confident transition for new residents. It is essential that an individual's human rights are protected and actively endorsed within the care home environment. Moreover, individuals need be able to access any advice and information they may

require when making informed choices including accessing health care, community, and advocacy services.

#### Psychological support

This study identified the necessity of increasing recognition of older people's need for continuing psychological and emotional support. An appointed staff member could be identified to facilitate the assessment, management, and support of the psychological and emotional needs of the individual experiencing bereavement and loss. This might include identifying each person's initial and ongoing hopes and expectations. In addition, older people and their family need to be supported to engage in honest and caring discussions to help with acceptance and adaptation to living in a care home while embracing the heart of 'home'.

#### Social care support

It is recommended that care home managers energetically pursue opportunities to engage with the wider community and look for voluntary and community organisations to facilitate individualised social care support. An effective management resource for promoting quality of life and positive change in care homes is offered by My Home Life (<https://myhomelife.org.uk/>). This international programme provides leadership support to managers by increasing knowledge and skills in effective management to inspire and direct culture change within care homes (Penney and Ryan, 2018). In addition, My Home Life facilitates community engagement events and inter-generational activities that create a sense of community between residents, family, care home staff and local communities.

## **6.5 Recommendations for Education**

### **Gerontological nursing as a positive career choice**

The role of a gerontological nurse requires much more recognition within the field of education and clinical practice. The development of pre and post registration nursing programmes could be enhanced by incorporating the views of older people and facilitating access to experienced gerontological nurses across all settings. A nurse's decision to pursue a career in gerontological nursing can be influenced by their experiences in a range of care facilities at pre and post registration level. Education and health and social care providers, working collaboratively, have the potential to facilitate effective learning experiences for undergraduate and postgraduate student nurses and to promote gerontological nursing as a positive career choice.

### **Continuing professional development**

The findings from the study highlight the importance of involving 'the person' in making the decision to move and having a choice of care home which has a hugely significant impact on their experience of transition and adaptation thereafter. Health care professionals play a critical role in facilitating this process, therefore supporting them through continuing professional development programmes with an emphasis on the specific needs of older people making the transition to a care home environment, need to be provided.

This study provides tentative evidence to suggest that the ageist attitudes of health and social care staff may have influenced the extent to which participants were involved in the decision-making process across the four time points of the study. There is a

need to challenge these views so as to ensure that the human rights of older people are recognised and respected across all settings including care homes.

## **6.6 Study Limitations**

The focus of the study concerned older peoples' perspectives on moving from home to a care home over a one year period. The views of other key stakeholders involved in the transition process (e.g. families, hospital staff, community care managers, care home staff) may have offered additional insights. However, this must be considered in the context of the large body of evidence that exists with respect to the families' perspectives and involvement in care home transition in comparison to the paucity of research on residents' experiences. That said, the views of health care professionals could have added a further perspective, and this is a recommendation for future research in this field.

Secondly it is recognised that a significant number of people residing in care homes have been diagnosed with dementia or severe memory problems ([Alzheimer's Society, 2019](#)). However, as the study was carried out over a 12-month period and relied on the ability of participants to recall and reflect on their experiences in an interview situation, it was important to select participants who were able to do this and in doing so, to give voice to individuals who are often excluded from this type of research.

Thirdly, the cultural context in which older people making the move from home to a care home is based on white Caucasian participants living in the UK. These experiences should be examined in other ethnic groups not represented in this study.

## 6.7 My PhD Journey

In the introductory chapter I outlined how I obtained an Institute of Nursing Fellowship from Ulster University to undertake a research study to determine the prevalence of mental health disorders among older people in care homes. The study findings prompted me to think about the factors that influence an individual's perception of living a positive and fulfilling life in a care home and pursue these issues at doctoral level study. Also, I outlined how having been a care home manager for several years prior to becoming a nurse lecturer gave me insight into the care managerial role.

From the outset I became very aware that the individuals I sought to engage within this thesis study were deemed to be a 'vulnerable population' both by my professional knowledge, and through partaking in a formal ethics committee meeting to present the purpose and protocols for the study. The necessary and relevant protocol and POVA guidelines (DHSSPS, 2006) were developed and followed when required. However, what occurred to me very early in the recruitment phase was how protective social workers and some care home managers were about facilitating access to potential participants. Having had meetings with both these groups of professionals, many of the comments I received were *"we would never have the kind of people you are looking for"*, *"they all have dementia"*, *"old people want peace, they don't want to be bothered with research"*. They said they were also 'under pressure' and it was evident that facilitating a research project was not on the agenda *"we have no staff"*, *"I have a big workload I don't have time for this"*. However, I did have some positive affirmations also in terms of *"I have a great lady for you who is hoping to move soon"*

or “*we would love to be doing research with the university, it is important what older people have to say*”. It is interesting that those managers who contacted me to identify potential participants were also “under pressure” but saw the value and importance of undertaking this research. As the study progressed, I often reflected how the ‘protective’ position could be justified, as it was at odds with how some participants viewed the level of protection and support, they received during the move to the care home, with some participants feeling ‘*helpless*’.

During the course of this study, I kept a reflective diary along with my theoretical journals and memos. This diary gave me an opportunity to reflect on issues that were happening during the interviews that had a heartfelt effect on my thoughts and emotions. I have made several entries about feeling emotional hearing the circumstances surrounding some participants move to the care home especially when grieving the loss of a family member or home. I have also felt annoyance at the lack of rehabilitative services provided within care homes when contrasted with that delivered in the community. As a former manager I could empathise with the complex nature of managing a care home but I was disappointed on more than one occasion when I observed people asking and waiting a long time for assistance as care workers stood by and did not respond and I found myself intervening a few times. However, I also witnessed some amazing examples of how care home staff offered friendship, hope, and purpose. They genuinely valued each care home resident as part of the ‘care home family’. I also gained some insight into how strict and restrictive practices are perceived to have a negative effect on individuals and that how ‘treating everyone the same’ may cause some people to avoid expressing their individuality, becoming passive and conforming to set routines within the home.

During the course of this doctoral study I sought to become more aware of my own reactions to what participants were saying to increase my awareness of my own intrinsic bias. At times I have felt really perturbed in relation to some of the comments participants have made for example, Bernadette said *“I get especially emotional about people dying in here, like when I see that there’s two coffins that have gone past my door. Then I wait for them to come back down again you know.... I get upset when they are taking them to the hospital or wherever they take them... and you see, you start to get used to these things.... going back and forward. I can see that out of the door”*. This statement was expressed in a similar way by another participant in a different care home and I often reflected how this must remind people of their own mortality. I also thought about why carers did not close the door out of respect, or else actively involve residents that had formed friendship bonds to engage in saying their goodbyes to the person. It was as if they were blind to how this may be perceived by older people. I realised that I felt appalled that dignity was not preserved for the deceased and the living.

Finally, I appreciate that previous personal and professional knowledge does have an influence on the entire research process from recruitment, to data analysis and write up. Being reflexive means being transparent about decisions that are made in the research process (Engward and Davis, 2015). For the duration of this PhD journey I have realised the importance of questioning my decisions about data analysis including undertaking constant comparative analysis and theoretical sampling. By questioning what the data is saying, including contextual factors into the analysis,

alongside continual critical self-reflection, I have done my utmost to tell the story as it was told to me.

## 6.8 Future Research

The theory that emerged from this grounded theory study '*The centrality of connection in supporting older people on their journey from life at home to life in a care home*' suggests that care home residents who are connected, as evidenced by their participation in decision making about the move, and who can maintain existing connections to their former home life and family while creating new connections within the care home have a more successful transition to life in a care home than individuals who do not have this connectedness. This study's findings advocate changing the portrayal of life in a care home. The intention is not to try and replace an individuals' connections with 'home' but rather support a parallel focus of maintaining existing connections to their former home life and family while creating new connections within the care home.

Building on findings from this study, there is a need for future research to investigate the perspective of health care professionals involved in supporting older people in making the move to a care home. Informed research can advise policy makers and service providers on how to meet older person's health and social care needs prior to, during and following relocation to a care home.

Future research needs to explore the effects of organisational, regulatory, cultural and system factors on care home transition. Care transition, planning and management




requires a research framework to identify innovative systems of stakeholder involvement so as to acknowledge the central connection of older people and their families in the decision making process of moving to a care home as well as to define professional and cultural drivers of shared responsibility.

## Appendices

### Appendix 1: Manuscript decision

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Health & Social Care in the Community - Manuscript ID HSCC-RA-20-0332.R2





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To: O'Neill, Marie

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18-Aug-2020

Dear Ms. O'Neill:

Your manuscript entitled "The 'Primacy of 'Home': An exploration of how older adults transition to life in a care home towards the end of the first year." has been successfully submitted online and is presently being given full consideration for publication in Health & Social Care in the Community.

Your manuscript ID is HSCC-RA-20-0332.R2.

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Thank you for submitting your manuscript to Health & Social Care in the Community.

Sincerely,  
Health & Social Care in the Community Editorial Office

## Appendix 2: Critical Appraisal Skills Programme Qualitative Checklist (CASP, 2018)

Author and year	Q1 Was there a clear statement of the aims of the research?	Q.2 Is qualitative methodology appropriate?	Q.3. Was the research design appropriate to address the aims of the research?	Q.4. Was the recruitment strategy appropriate to the aims of the research?	Q.5. Was the data collected in a way that addressed the research issue?	Q. 6. Has the relationship between researcher and participants been adequately considered?	Q. 7. Have ethical issues been taken into consideration?	Q. 8. Was the data analysis sufficiently rigorous?	Q. 9 Is there a clear statement of findings?	Q.10 How valuable is the research? Links to literature and clinical practice
Andersson et al. (2005)	✓	✓	✓	✓	✓	CT	✓	✓	✓	N
Brandburg et al. (2012)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Cooney (2012)	✓	✓	✓	✓	✓	CT	✓	✓	✓	✓
de Guzman et al. (2012)	✓	✓	✓	✓	✓	CT	CT if ethical approval granted. Consent yes.	✓	✓	✓
Falk et al. (2012)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Fraher and Coffey (2011)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Heliker and Scholler-Jaquish (2006)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

Hutchinson et al. (2011)	✓	✓	✓	✓	✓	CT	✓	✓	✓	✓
Iwasiw et al. (1996)	✓	✓	✓	✓	✓	CT	✓	✓	✓	✓
Iwasiw et al. (2003)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Johnson and Bibbo (2014)	✓	✓	✓	✓	✓	CT	✓	✓	✓	✓
Koppitz et al. (2017)	✓	✓	✓	✓	✓	CT	✓	✓	✓	✓
Krizaj et al (2018)	✓	✓	✓	✓	✓	CT	✓	✓	✓	✓
D.T.F Lee (1999)	✓	✓	✓	✓	✓	CT	CT ethical approval. Consent yes	✓	✓	CT
Lee et al. (2002)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Lee et al. (2013)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Paddock et al. (2018)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Reed and Payton (1997)	✓	✓	✓	✓	✓	CT	CT	✓	✓	✓
Stevens et al 2015	✓	✓	✓	✓	✓	CT	✓	✓	✓	CT
Sussman and Dupuis (2014)	✓	✓	✓	✓	✓	CT	✓	✓	✓	✓
Wilson S.A. (1997)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Zamanzadeh et al. (2015)	✓	✓	✓	✓	✓	CT	✓	✓	✓	CT

N.B\* Y= Yes N=No CT= Can't Tell

### Appendix 3: Critical Appraisal Skills Programme Systematic Review Checklist (CASP, 2018)

Author and year	Q1 Did the review address a clearly focused question?	Q.2 Did the authors look for the right type of papers?	Q.3. Do you think all the important, relevant studies were included?	Q.4. Did the review's authors do enough to assess quality of the included studies?	Q.5. If the results of the review have been combined, was it reasonable to do so?	Q. 6. What are the overall results of the review?	Q. 7. How precise are the results?	Q. 8. Can the results be applied to the local population?	Q. 9 Were all important outcomes considered?	Q.10 Are the benefits worth the harms and costs?
Bradshaw et al. (2012) 7/10	Y	Y	Y	CT	Y	No statistics	No	Y	Y	Y
Brandburg (2007) Integrative Literature Review	Y	Y	Y	CT	Y	A Proposed Transition Process Framework	No confidence intervals	Y	CT	Y
Brownie et al. (2014)	Y	Y	Y	Y	Y	No statistics	No confidence intervals	Y	Y	Y
J.M Ellis (2010) DISCUSSION PAPER? <b>REMOVE 5/10</b>	Y	Y	CT	CT	Y	A theoretical understanding of the psycho-logical transition	No confidence intervals	CT	CT	Y
Fitzpatrick and Tzouvara (2018)	Y	Y	Y	Y	Y	No statistics	No confidence intervals	Y	Y	Y
Lee et al. (2001)	Y	Y	Y	CT	Y	No statistics	No confidence intervals	Y	Y	Y
Rijnaard et al. (2016)	Y	Y	Y	CT	Y	No statistics	No confidence intervals	Y	Y	Y
Sullivan and Williams (2017)	Y	Y	Y	CT	Y	No statistics	No confidence intervals	Y	Y	Y

Note: Key: Y = "yes"; N = "no"; CT = "can't tell"

#### Appendix 4: Table of Studies

Author(s) Country	Aims	Participants	Design and Methods	Results
Andersson et al. (2007) Sweden	To describe older people's experiences of daily life at the care home after admittance with respect to their perceptions of participation in the decision to move. Also, the aim was to study the experiences of their relatives and contact persons with respect to the daily life of the same residents.	Purposive sample n=13 residents, recently admitted to a care home, 69–90 years old, both single living and married, both moving from their own homes and from different institutions who had lived up to two months at the care home.	Qualitative design. Interviews were carried out with the older people (n = 13), their relatives (n = 10) and contact persons (n = 11)	The findings indicated that the majority of the residents were satisfied with living in the care home. All of the satisfied residents, except one, had participated in the decision to move into the care home. Three residents reported dissatisfaction and two of them had not participated in the decision to move. Two of the dissatisfied residents did not find the move desirable, voluntary or legitimate.
Brandburg et al. (2012) USA	To identify strategies that older adults use to adapt to live in long-term care.	21 participants, 17 women and four men aged from 65–93 years, mainly Caucasian with one African American and one Hispanic. Length of stay 3 days to over 9 years living in LTC recruited from three nursing homes	A qualitative research design, using a grounded theory approach. A total of 30 interviews were completed with a purposive sample of 21 participants (21 initial and 9 follow-up interviews)	The results of this study yielded 21 facilitative strategies. The core category identified was personal resiliency, which served as the underpinning for the strategies used by the participants. Strategies were identified in making the decision to move into long-term care and in day-to-day living.
Cooney (2012) Ireland	This study aimed to understand older peoples' perceptions of 'being at home' in long-term care settings and the factors that influence these perceptions	Residents (n = 61) living in four types of LTC facilities. N=17 male and n=44 female. Age range 65-90 plus	Grounded theory methodology using unstructured interviews. To capture different perspectives, participants with different experiences were initially interviewed (purposive sampling).	Four categories were identified as critical to finding a home in long-term care settings: 'continuity', 'preserving personal identity', 'belonging' and 'being active and working'. 'Finding Home' was conceptualised as the core category. The potential to 'find home' was influenced by mediating and

			This included newly admitted residents, those who had lived in the facility for longer than 3 months, younger and older residents and men and women	facilitating/constraining factors .The Theory of Finding Home (ToFH) describes the factors central to 'finding home' in long-term care settings and identifies how nurses can support residents in their quest to feel at home.
De Guzman et al. (2012) Philippines	This study was undertaken to explore the process of adapting of the elderly to the change in their environment and the emotional transition starting from admission until their acclimatization in a residential care facility	20 older Filipino adults aged 60–84, mentally competent, and conversant were recruited.	Grounded theory methodology. Individual interviews were conducted with participants who had moved to the residential care facility for at least six months.	An Hourglass of Acclimatization model emerged. This model yielded two distinct phases contributing to successful acclimatization. One is the Conversion phase or imbibing the main notion of transforming one's perspectives of him or herself and his or her environment; there is also the Immersion phase, which describes how an elderly involves him/ herself completely into the life he or she is supposed to live. This emerged model can contribute to the development of nursing interventions focusing on the entire course of relocation to a new environment.
Falk et al. (2012) Sweden	The aim of this study was to gain a deeper understanding of the processes involved, and the strategies by which older persons create a sense of home, place-attachment, and privacy in residential care facilities.	25 respondents (21 women and four men) mean age 82 year for both men and women. The mean length of stay at the residential facility at time of interview was for both sexes 9 months	Constructivist grounded theory. Individual interviews. Grounded theory analysis with simultaneous theoretical sampling and interpretation of data developing and refining the portrayal of experiences through the construction of theories	Findings show that a sense of home in residential care involves strategies related to three dimensions of the environment – attachment to place, to space and attachment beyond the institution –and that the circumstances under which older people manage or fail in creating attachment, consist of psychosocial processes involving both individual and shared attitudes and beliefs.
Fraher and Coffey (2011) Ireland	The aim of this study was to explore older people's experience of the decision to relocate to long-term care and their early experiences post-relocation.	A purposive sample of (n=8) over the age of 65 years. n=2 male aged 78 and 86 and n=6 female 80 to 92 years. Participants had to achieve a cognitive	A hermeneutic phenomenological approach was adopted through an interpretation of narrative text. individual audio-taped interviews were conducted and analysed using Colaizzi's (1978) phenomenological method.	There was considerable evidence that decisions about moving to long-term care were poorly handled, with inconsistencies, lack of choice and involvement in decisions. although some individuals had anticipated their move, decisions were often made hastily with little or no planning. Individual experiences differed according to people's respective

		score of more than 23 using the Mini-Mental test score (MMTs) (Folstein et al 1975) and in LTC no longer than three months.		contexts, history and the events that led to the move. People accepted, and adjusted to, their new situation more quickly when the admission was planned.
Heliker and Scholler-Jaquish (2006) USA	the objectives of this study included: describing the phenomenon of being admitted and living in a nursing home from residents' perspectives, explicating key transitions in residents' experiences during their first 3 months in the facility; and developing evidence-based strategies to ease the transition process.	A convenience sample of 10 volunteers was selected from newly admitted residents who had to attain a MMSE (Folstein, Folstein, & McHugh, 1975) score greater than 24	Hermeneutical phenomenology (Benner, 1994; Heidegger, 1927/1962). Convenience sample of 10 participants were interviewed within 1 week of admission and then periodically during the next 3 months. Thirty-two verbatim interviews were analysed using interpretive phenomenology	The following three constitutive patterns of transition to nursing home living emerged: I Becoming homeless. I Getting settled and learning the ropes. I Creating a place. Understanding residents' experience of transition leads to innovative practice changes in anticipation of individuals' needs. Recommendations for the delivery of consumer-directed care are offered.
Hutchinson et al. (2011) USA	The aim of this study was to investigate person and environment factors of elders that facilitate adaptation to relocation to long-term care skilled nursing facilities	N= 23 elders from n=6 LTCFs. Sample was limited to African Americans and Caucasians aged 60 + who resided in an LTCF 6 months or less and scored 5 or less on the Short Portable Mental Status Questionnaire (Pfeiffer, 1975)	Phenomenology- Qualitative interviews. Two tested qualitative instruments were used to obtain information regarding personal and cultural heritage factors. The Life Narrative Interview (Gubrium, 1975/1997) and The Cultural Heritage Interview (Spencer & Hersch, 2000)	Themes that emerged included (a) spirituality, death and dying, and philosophy of life; (b) life experiences with change; (c) cultural heritage; (d) health; (e) ethnicity; (f) social support, family, and friends; (g) long-term care facility (LTCF) relationships; (h) LTCF system maintenance; and (i) LTCF support of personal growth. Comparison of African Americans and Caucasians showed more similarities than differences between the groups.
Iwasiw et al. (1996) Canada	The specific research questions were: 1. What are the experiences of newly admitted residents in the	N=12 residents aged between 67 and 96 years in five LTCF's (10 women and two men).	A Qualitative study was conducted with purposive sampling. Constant comparative method of qualitative analysis originally described by	Experiences were classified into four categories: <ul style="list-style-type: none"> <li>• Emotional reactions</li> <li>• Transition activities</li> <li>• Reflecting on their situation,</li> </ul>



	<p>first 2 weeks in a LTCF following relocation from home?</p> <p>2. What are the needs, priorities, and expectations of residents during their first 2 weeks in a LTCF?</p> <p>3. What are the residents' views about how this relocation can be facilitated?</p>	<p>All had been admitted directly from home. Participants were required to attain a score of at least 24 on the Mini-Mental State Examination (Folstein et al. 1975)</p>	<p>Glaser and Strauss (1967) was used.</p>	<ul style="list-style-type: none"> <li>Connecting with a personal philosophy</li> </ul> <p>Generally, conditions which seemed to influence the experience of the first 2 weeks were whether residents had their desired amount of involvement in planning for the move, the meanings they attached to the experience, and their emotional state.</p>
<p>Iwasiw et al. (2003) Canada</p>	<p>The purpose of this study was fourfold:</p> <ul style="list-style-type: none"> <li>To explore residents' perspectives of their first year in a LTCF after relocation from home.</li> <li>To explore perceptions of close family members of the residents' situation in the LTCF.</li> <li>To determine the needs, priorities, and expectations of residents and family members.</li> <li>To ascertain residents' and family members' view of desirable challenges for the first year.</li> </ul>	<p>Participants (n=6) Five men and one woman aged between 75 to 88 years residing in two long term care facilities. (n=5) had participated in the decision to move either alone or with a family member and came directly from home. Three family members participated in interviews.</p>	<p>A longitudinal study using narrative method and semi-structured interviews with residents and family members. Resident's and family members were scheduled to be interviewed six times- at 2 and 6 weeks, and 3,6,9, and 12 months following the resident's relocation. However, not all participants remained for an entire year and because of staged participant accrual the total period of data collection was 2 years. Because some participants were unable to remain in the study for the full year a total of 31 interviews were obtained instead of the 54 anticipated.</p>	<p>Themes emerging from resident and family perspectives.</p> <ol style="list-style-type: none"> <li>Decision making associated with moving in.</li> <li>Fitting in.</li> <li>Maintaining previous relationships and establishing new ones.</li> <li>Emotional reactions.</li> <li>Reflecting on the situation.</li> <li>Maintaining identity: Personhood.</li> </ol> <p>The majority of residents appraised the LTCF negatively, particularly after 3 months. Recognising their vulnerability, they and family members stated they were reluctant to voice complaints to staff.</p>
<p>Johnson and Bibbo (2014) USA</p>	<p>Questions posed were:</p> <ul style="list-style-type: none"> <li>How does the concept of home emerge in older adults who have recently</li> </ul>	<p>Participants (n=8) were part of a larger . Eligibility requirements were</p>	<p>Interpretive phenomenological approach which was part of a longitudinal study investigating the transition into nursing home</p>	<p>Statements of participants differed between the first interview and the second in the ways in which they applied the concepts of place, possessions, safety, and autonomy to their new setting. While still feeling</p>

	<p>relocated into a nursing home?</p> <ul style="list-style-type: none"> <li>To what extent does the concept of home change following a period of potential adjustment?</li> <li>In what way does the degree of perceived control over the decision making process seem to be related to the sense of home developed in a nursing home</li> </ul>	that the participant be admitted to the facility within the previous two weeks and have a minimum score of 18 on the Mini Mental State Examination in order to assure cognitive functioning.	facilities for older adults across three ethnic groups, African-Americans, European-Americans, and Latinos to uncover how eight older adults in nursing homes in the Midwestern U.S. constructed the meaning of home shortly following the relocation and again approximately two months later.	strong loyalties to their previous homes, they had by the second interview begun to meet people, and in particular to attach the concept of safety and availability of care to their new residence The majority of individuals did not consider the facility to be “home,” but actively changed their attitudes toward the facility and themselves to better adjust to the setting. The findings demonstrate the importance of autonomy in older adults' definitions of home.
Koppitz et al. (2017) Switzerland	The aim of this study was to gain an in-depth understanding into unplanned admissions to nursing homes and to explore its impact on adaptation. This study was part of a larger, two-phase, retrospective, descriptive study entitled "SANS (Swiss Admission to Nursing home Study)."	Participants (n=31) N=8 males and n=23 females were recruited in n=4 nursing homes. Mean age 83.1 years, had been living in the nursing home for over two weeks and up to 93 months	Qualitative interview design based on Meleis' transition model. This paper presents the findings from the second phase. The (n=31) interviews were used to explore the relevant, in-depth experiences of older adults who were confronted with unplanned admission and were analyzed using Mayring's qualitative content analysis (2010)	This study presents a model of analysis to evaluate patterns of adaptation following an unplanned admission to a nursing home after hospital discharge. The following four patterns of adaptation emerged from the analysis: "being cut-off," "being restricted," "being cared for," and "moving on." The patterns evaluate the relocation into nursing homes and provide an opportunity to appraise the stages of adaption.
Krizaj et al (2018) Slovenia	The aim of the current study was to explore Slovenian older people's experiences of transition into a care home and how it influenced their everyday engagement in meaningful occupations	Participants (n=6) aged 74–92 years old were recruited via a gatekeeper who was a social worker in one Slovenian care home.	Interpretative Phenomenological Analysis (IPA) approach for both data collection and data analysis. Semi structured interviews were conducted at three time intervals: before the relocation, 1 month after, and 6 months after the relocation into a care home.	Overarching themes developed from interviews were: “Holding on to what I do,” “The significance of others through transition,” and “The time of loss and acceptance.” The overarching theme “Holding on to what I do” with superordinate themes of “This is who I am”, “Adjusting my daily occupations”, and “The value of health” were discussed. The remaining two themes will be presented in future publications

D.T.F Lee (1999) China	<p>The aim of this study was to achieve understanding of how Chinese elders experience the changes associated with admission to residential care homes. The following research questions formed the analytical core of the study:</p> <ul style="list-style-type: none"> <li>• What are the experiences of Chinese elderly residents newly admitted to residential care homes?</li> <li>• How do these experiences affect residential home life?</li> </ul>	The participants (n=10) included four male and six female residents. They were aged from 68 to 88 years. Residents were admitted to this home within 1 week with no hearing or speech problems.	A qualitative study design which sought to identify, describe, and understand the thoughts and experiences of individuals was selected as the relevant methodological paradigm for this study. Both latent and manifest content analysis (Morse & Field 1996) were conducted. Interviews focused on exploring what the first week's experience was like for them and how they settled into residential life.	Content analysis of the interview data revealed the significance of cultural influences in the transition experiences. A number of issues suggested in the literature as barriers to adjustment to residential care, such as living with rules and regulations, lack of privacy and autonomy were not regarded as important by the Chinese elders. The Chinese values of balance, harmony and collectivism made it easier for them to remain open and accept the communal way of living. Yet, these same values restricted the elders in developing new relationships with staff and other residents. This appears to be the particular challenge facing Chinese elderly residents.
Lee et al. (2002) China	The aim of this study was to describe the process through which Chinese elders adjust following nursing home placement.	n= 18 elderly residents (9 men and 9 women) Age range 70 -86 years.	Grounded theory methodology was employed. Data were collected from 98 interviews with n= 18 residents newly admitted to a nursing home in Hong Kong one week after admission and then monthly until no new information about their adjustment experiences could be discovered. Data were analyzed using constant comparative analysis.	Newly admitted elders adjusted through the four stages of orienting, normalizing, rationalizing, and stabilizing as they struggled to regain normality with a life that was as close to that lived before admission as possible. A number of experiences suggested in the literature as barriers to adjustment, such as living with rules and regulations, and the communal nature of nursing home life were not regarded as important by Chinese elders. However, establishing relations with other residents was a particular challenge for them.
Lee et al. (2013) UK	This research aimed to explore qualitatively older people's experiences of this transition, including how relocation is reflected upon and	Eight older adults (65–97 years) living in a residential facility for between three and 12 months.	Narrative analysis. Specific points of interest for the authors included: the sequencing and tone of each story, main characters in relation to the narrator, language structure, metaphor/	Narrative analysis revealed that rather than depicting time bound stages of transition, participants' experiences reflected key plots of 'control', 'power', 'identity' and 'uncertainty' interwoven throughout their narratives. Participants experienced some difficulties in incorporating this transition into their

	incorporated into their personal narratives.		imagery, repetition, the wider cultural context, and the sense of identity presented within the data	life stories. Furthermore, participants discussed not feeling confident in their decision to move, living in constant fear of losing their memory, and limited expectations for their future.
Paddock et al. (2018) UK	This study explores how living in a care home affects the identities of residents and how they address this in their daily lives.	Residents aged over 65 years; all staff who had regular contact with residents; all visitors who were a relative or long-term acquaintance of a resident. (n=9) residents (n=4) relatives (n=5) staff	A multiple qualitative case study approach incorporating interview and observational data within n=3 care homes; n=18 semi structured interviews and 260 hr of observations were conducted over 1 year with residents, relatives, and staff across three care homes. Data framework analysis, drawing on the social identity perspective as an interpretive lens.	Four themes were identified: (a) changing with age, (b) independence and autonomy, (c) bounded identity, and (d) social comparison. The impact of aging that initially altered residents' identities was exacerbated by the care home environment. Institutional restrictions jeopardized independence and autonomy, provoking residents to redefine this within the allowances of the care home. Strict routines and resource constraints resulted in the bounded expression of personalities.
Reed and Payton (1997) UK	This study aimed to examine the processes of adaptation that older people engage in when moving into care homes,	N=40 older adults n=10 focus groups with 3-6 staff. N=6 care homes in one local health authority	Qualitative study with thematic analysis. Semi structured interviews before the move, at 3 months post move, last interview before 6 months. A second strand to the study involved conducting focus groups interviews with care home staff.	Theoretical categories crossed over topics, such as the 'settling in' processes and involved a range of different dimensions, ranging from the physical environment to interpersonal relationships. The disparity between the views of residents and staff suggests that the importance of other residents' support and companionship, is poorly understood by staff. Residents are active in their social world, which they describe in detail and appear to value highly.
Stevens et al 2015 UK	This study aimed to explore the experiences of older people with minimal care needs admission to care homes with Registered Nurse (RN) care. A key objective was to develop an understanding of why older people with minimal care needs	12 residents (ten women and two men), aged 86-99 years, participated in the study. Five were admitted to a care home from hospital	A qualitative study using a grounded theory method was undertaken. Initial sampling was purposive and progressed to theoretical. Interviews were analysed using the grounded theory analysis method of constant comparison and theory	Two main categories emerged: "choosing the path", which concerned the decision to enter the home, and "settling in", which related to adaptation to the environment. Findings suggested participants who perceived they had greater control over the decision-making process found it easier to settle in the care home. The two categories linked to form an emerging framework of "crossing the bridge" from

	chose to live in care homes with RN care	and seven from their own home.	development. Length of time living in care home prior to interview is not stated.	independent living to care home resident. The findings contribute to the understanding of factors influencing admission of older people with minimal care needs to care homes with RN care and highlight the importance of informed decision making.
Sussman and Dupuis (2014) Canada	Research questions: (a) What conditions help or hinder older adults' positive experiences with each phase of the relocation process including the decision-making phase, the move itself, and the initial post-move adjustment? and (b) how do the presence or absence of conditions from one phase of the process influence residents' experiences with subsequent phases?	N=10 participants from three LTCF's. Aged 75-97 years. Females n=8 and males n=2. Residents who had newly relocated for no longer than 6 weeks.	Grounded theory methodology with selective purposive sampling. Explored residents' experiences with three stages of the relocation process: pre-move decision making, moving, and post move adjustment.	Residents' accounts revealed a complex and layered intersection of conditions that shaped their experiences at each stage of the relocation process. When conditions at individual, interpersonal, and/or systemic layers nurtured a sense of control, and respect for personhood, residents reported positive relocation experiences and their ability to develop a sense of comfort and belonging within LTC was facilitated. Conversely, when conditions at one or a series of layers threatened or challenged control and respect for personhood, residents reported negative experiences that compromised their subsequent adjustment to LTC
Wilson S.A. (1997) USA	The purpose of this study was to identify variance in the initial responses of older adults whose move to a nursing home is expected to be a permanent move.	Fifteen older adults, 11 females and 4 males, ranging in age from 76 to 97 years comprised the sample. All were of EuroAmerican origin.	A grounded theory approach was used in this exploratory and descriptive study. The primary data collection methods were in-depth semi structured interviews every other day for 2 weeks, 1 month post-admission. and field notes of the interviews and observations.	Data analysis demonstrated that the transition to nursing home life occurred in three phases: overwhelmed, adjustment and initial acceptance phase. The major theme of adjusting to nursing home life was protection and maintaining a facade of normalcy. Issues relating to autonomy and control are significant in the older adults' adjustment to the nursing home. The rules and regulations of the nursing home presented problems for older adults in adjusting.
Zamanzadeh et al. (2015) Iran	This exploratory qualitative study aimed to describe the experiences and psychosocial effects of transitioning from	(n=17) participants (range 62–91 years). Length of stay in the ACH was 11 months	This exploratory qualitative study. Purposive sampling was used to recruit a convenience sample of	The psychosocial effects of transitioning are categorised into four themes: communication isolation, resource change, monotone institutional life, and negative emotional response. Participants

	home in the community to an ACH for older Iranian people.	(range 1–48 months). The three staff caregivers (range 29–44 years).	older people and caregivers. Semi-structured face-to face interviews. Data were analysed by means of conventional qualitative content analysis technique.	lost their previous support systems when transitioning and were not able to establish new ones. Routine care was provided by formal caregivers with little attention to individual needs, and minimal support was given to help maintain the older person's independence. These losses gave rise to negative emotions in some of the participants.
<b>LITERATURE REVIEWS</b>				
Bradshaw et al. (2012)	To collate the views of different types of people living in care homes, including younger adults, and those with dementia and disabilities.	Aim is to produce a systematic review of qualitative studies that have examined residents' views of QoL. Specifically, it aims to identify and summarise the factors that positively influence care home life.	Systematic qualitative review PsycINFO, Medline, Web of Science, EMBASE, Allied and Complementary Medicine Database and Cumulative Index to Nursing and Allied Health Literature. Thematic analysis and meta-ethnographic methods were adapted to synthesise findings. Thirty-one studies were identified.	People in care homes voiced concerns about lack of autonomy and difficulty in forming appropriate relationships with others. For a good QoL in care homes, four key themes are necessary: the person's 'acceptance and adaptation to their living situation', their 'connectedness' with others, living in 'a homelike environment' and carers displaying 'caring practices'. This review also supports and extends the finding that a positive approach to living in care homes is associated with effective coping and adaptation.
Brandburg (2007) USA	Older adults' perspectives of making the transition and adapting to long-term placement in the nursing home.	The primary focus of the search was to locate articles identifying older adults' perspectives on the transition and adaptation process postadmission to a nursing home.	Integrative literature review. Databases searched included Ovid, Cumulative Index to Nursing and Allied Health Literature (CINAHL), MEDLINE, PsycINFO, Sociological Abstracts (SocAbs), and Health Source: Nursing/Academic Edition	The literature shows exploratory descriptive research has identified many variables important in the transition process. A transition process framework was developed from the findings. There were four components to the transition process framework: (i) Initial reaction., (ii) Transitional influences, (iii) Adjustment and (iv) Acceptance (viewed as either maladaptive or adaptive).
Brownie et al. (2014)	To identify the factors that impact residents' transition and	Inclusion criteria: Low or high-care residents	Systematic literature review: The concept of home and Bridges'	Key determinants of residents' relocation experience included the extent to which they were able to exert

Australia	adjustment to long-term aged care and influence their relocation experience	in aged care facilities (not retirement villages, hospitals, or hospices), also known as nursing homes or long-term aged care facilities; residents without any cognitive impairment.	three stages of transition framework provided conceptual models. METHOD: Databases Academic Search Premier, Cinahl, Medline, PysciINFO, Psychology and Behavioral Sciences Collection and Scopus	control over the decision to move to an aged care facility, preserve their autonomy, and retain meaningful social relationships. Encouraging the development of new relationships with other residents and staff is an important role for staff to play while providing residents with opportunities to talk about their feelings, their life experience, and their involvement in the decision to relocate.
Fitzpatrick and Tzouvara (2018) UK	The aim of the review was to address the question: What factors facilitate and inhibit transition for older people who have re-located to a long-term care facility?	A systematic review that examines transition conditions for older people who have relocated long-term care facility to include older people, families, and care facility staff. Eliciting multiple perspectives aims to achieve a fuller understanding of what might shape a healthy transition for older people.	Databases searched from 01/90 to 10/17 were: PysciINFO, British Nursing Index, CINAHL, MEDLINE and Web of Science. A supplementary search strategy was searching the reference lists of all included studies. Grey literature searches were conducted using Google Scholar, and Social Science Research Network (SSRN)	A narrative synthesis was conducted informed by Meleis's Theory of Transition. Thirty-four studies (25 qualitative, 7 quantitative and 2 mixed methods) met the inclusion criteria. Data synthesis identified that transition following relocation was examined using a variety of terms, timelines, and study designs. Potential personal and community focused facilitators and inhibitors mapped to four themes: resilience of the older person, interpersonal connections, and relationships, this is my new home, and the care facility as an organisation. These findings can inform the development of interventions for these target areas. They highlight also that further research is warranted to understand organisational culture of long-term care facilities.
Lee et al. (2001) China	The purpose of this paper is to review and synthesize the literature related to older people's experiences with residential care placement. Articles from the years 1970±2000 were selected for inclusion on the basis that they	Articles from the years 1970±2000 were selected for inclusion on the basis that they either investigated older people's experiences with residential care placement or the ways	Articles were identified through the CINAHL, PSYCINFO, MEDLINE, and SOCIOLOGICAL ABSTRACTS databases and through citations from published articles. The review begins with an analysis of the perception sand processes before and surrounding placement that	This review demonstrates that adjustment to residential care is more than just a discrete event. It begins well before placement actually, occurs and continues beyond. A body of knowledge relating to the preplacement experiences and processes that influence subsequent adjustment has been identified. While understanding of the postplacement experiences is increasing, research on the actual processes involved when older people adjust after

	either investigated older people's experiences with residential care placement or the ways in which elders cope with, master or succumb to the multitude of demands presented by residential care	in which elders cope with, master or succumb to the multitude of demands presented by residential care.	are found to shape older people's experiences upon entry to care. This is then followed by a critical analysis of postplacement adjustment, focusing specifically on synthesizing the experiences upon placement and how older people deal with these experiences.	the placement is still relatively scarce. Adjustment as a process that occurs and changes over time has not been adequately addressed in the literature.
Rijnaard et al. (2016) Netherlands	To provide an overview of factors influencing the sense of home of older adults residing in the nursing home	A systematic review was conducted. Inclusion criteria were (1) original and peer-reviewed research, (2) qualitative, quantitative, or mixed methods research, (3) research about nursing home residents (or similar type of housing), and (4) research on the sense of home, meaning of home, at-homeness, or home likeness	Five databases (CINAHL, PsycINFO, PubMed, Scopus, and Web of Science) were searched using a combination of two groups of keywords: (1) "meaning of home", "sense of home", and synonyms for these terms; (2) "care home" OR "nursing home" and similar search terms. Thematic synthesis was used to synthesize data into factors.	The sense of home of nursing home residents is influenced by 15 factors, divided into three themes: (1) psychological factors (sense of acknowledgement, preservation of one's habits and values, autonomy and control, and coping); (2) social factors (interaction and relationship with staff, residents, family and friends, and pets) and activities; and (3) the built environment (private space and (quasi-)public space, personal belongings, technology, look and feel, and the outdoors and location).
Sullivan and Williams (2017) USA	The purpose of the meta-synthesis was to provide an appraisal of older adults' transition experiences to LTC.	Inclusion criteria were recent qualitative studies (published between 2005 and 2015), conducted in the United States or Canada, published in	A meta-analysis and meta-synthesis reporting system was used to illustrate the deselection process of the compiled records (N = 181). There were 34 full-text articles, which were evaluated for eligibility. Of these articles, 26 were	Three themes were uncovered by this meta-synthesis: (a) painful loss that requires a mourning process, (b) seeking stability through gaining autonomy to sustain a new sense of self, and (c) acceptance when a unique inner balance is reached. The synthesis of the literature on older adults' transitions into LTC guided through MMRTT (Meleis



		English, with a focus on adults 65 or older transitioning to LTC. LTC was defined as nursing homes, skilled nursing facilities, and assisted living facilities.	subsequently excluded, resulting in nine to be examined using the systematic Critical Appraisal Skills Programme (CASP; 2013) scoring system.	et al., 2000) provided insight into healthy transitions (i.e., quality of life) for this population. The findings suggest that residents transitioning to LTC experience an inevitable loss; therefore, mourning the loss is necessary to progress through the transition. Residents expressed a longing for home as related to having autonomy, privacy, and activities that provide personal meaning; they wanted to be known and valued for who they are and what they have achieved in life.
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## Appendix 5: Interview Topic Guide



### Interview Topic Guide

**(1) A pre-residence** interview will be conducted with prospective participants to record their present day experiences, views on their current situation and expectations of life in the care home. Prompts may include

- ❖ Can you tell me a bit about the background to your move to a care home?
- ❖ Who else was involved in this decision?
- ❖ How did you choose the home you are going to?
- ❖ How do you feel about moving into a care home?
- ❖ Do you have any physical health problems /past?
- ❖ Do you have any problems with your mental health /past?
- ❖ Tell me a bit about your social life/hobbies/interests?
- ❖ What are your expectations about living in this care home?

**(2) Within 4 to 6 weeks** of arrival in the care home, participants will be interviewed again to determine their reactions to the setting. The interview will focus on perceived differences between expectations and experiences of the care home and between this and their own home. Expectations for the future and perceived physical, social, and psychological well-being of participants will be explored Topics will include:

- ❖ Tell me about the lead up to your move to this care home
- ❖ Talk me through the actual day of the move
- ❖ Do you still have contact with your family and friends from home?
- ❖ Do you think your life will change living in this care home?
- ❖ Do you have any concerns and/or worries over your future? Maybe include questions on physical, psychological, and social well-being at each interview

**(3) Approximately 4 to 5 months** after moving to care home participants will be interviewed again to discuss their feelings about making the commitment to permanent residence in the care home, if appropriate. Questions will be adapted from previous interviews to explore emerging themes. Topics will include:

- ❖ Describe your experiences of living in the care home?
- ❖ To what extent do you feel involved in making decisions regarding your care?
- ❖ Do you have choice in the things you do?
- ❖ What do you value?
- ❖ Who are the people who are most important to you? See above

**(4) A final interview at 9 to 12 months** will be undertaken. Participants will be asked to summarise the process of residence so far and to explore experiences of transition to living in a care home. Topics will include:

- ❖ Reflect upon your experiences since you came to live in the care home?
- ❖ How do you feel about living in the care home now?
- ❖ What are your plans for the future?
- ❖ What helped you adjust to life in the care home?
- ❖ What could have been done to help you to adjust to life in the care home?

**The interview schedule will evolve commensurate with category and subcategory dimensions using Grounded Theory approach.**

## Appendix 6: Letter to Case Managers



### Title of Research Study

**Residents' experiences of moving from home into a care home.**

### **Letter to Case Managers Intermediate and Acute Care Services WHSCT and Care Home Managers**

Dear

We would like to let you know about a research study that may be of interest to your patients/potential residents and ask you to consider referring your patients/potential residents for possible participation.

The study aims to increase our understanding of how adults make the transition from living in their own home to living in a care home within the Western Health and Social Care Trust (WHSCT) catchment area. The study will take place over a period of one year therefore it is important that patients/potential residents meet the following criteria:

- Are waiting for a care home placement
- Are aware that there is a planned admission to a care home.
- Are English speaking.
- Are able to communicate and understand communication.
- Have minimal cognitive impairment as defined by the Mini Mental State Examination (MMSE >24) (24 or over)
- Are able to understand the participant information sheet and have the capacity to provide informed consent.
- Are willing to consent to being interviewed on 4 occasions during the study

Ethical approval to conduct the study has been granted by Ulster University, Clinical and Social Care Governance, WHSCT and Office for Research Ethics Committees Northern Ireland. Indemnity for the study has been secured through the Ulster Research governance processes. A copy of the letter confirming indemnity is available from us on request. As a case manager we would be grateful if you would make initial contact with potential participants and provide them with the attached 'Letter of Invitation' to participate in the research study. **After you have done this, we will ask you to contact Mrs O'Neill as soon as possible if a potential participant consents to be contacted.**

We look forward to speaking with patients who may be interested in participating in this study. Please feel free to contact us with questions, using the contact information provided below.

Thank you for your time and consideration.

<p>Marie O'Neill Room MG207C Lecturer in Nursing Ulster University Magee Campus Londonderry BT48 7JL Tel: 028 71 675437 (direct line) E mail: <a href="mailto:m.oneill@ulster.ac.uk">m.oneill@ulster.ac.uk</a></p>	<p>Professor Assumpta Ryan Room MG105 Chief Investigator Ulster University Magee Campus Londonderry BT48 7JL Tel: 028 71 675350 (direct line) Email: <a href="mailto:aa.ryan@ulster.ac.uk">aa.ryan@ulster.ac.uk</a></p>
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## Appendix 7: Guidance Protocol on the approach to case managers nursing home managers



### Title of Research Study

Residents' experiences of moving from home into a care home.

#### **Guidance on the approach to case managers/care home managers.**

- I. As agreed, Mrs Marie O'Neill will telephone the Locality Service Managers based in the Northern and Southern sectors of the Western Health and Social Care Trust (WHSCT) to identify case managers who have clients that have been approved to receive financial funding for care home placement.
- II. Mrs Marie O'Neill will telephone identified case managers within WHSCT older people community teams and care home managers to provide background information about the research and to arrange an appointment to discuss the study.
- III. The initial face to face meeting with case managers/care home managers will inform them about the study and copies of the study documentation will be provided to managers during this meeting.
- IV. The case managers/care home managers will approach the potential participants and issue them with letters of invitation to participate in study. After the potential participant has had the opportunity to read letter of invitation the case managers/care home managers will approach the potential participants and request consent for their contact details to be passed to the researcher (see appendix 6).
- V. The case managers/care home managers will contact Mrs O'Neill to provide potential participant contact details. Once consent to approach the potential participant has been confirmed, Mrs O'Neill will telephone the participant to ensure that they are willing to participate and arrange an initial meeting.
- VI. Mrs O'Neill will then meet with potential participants to provide detailed information about research Study. This will be presented in a binder outlining a table of contents which will include an information sheet with contact details of the Research Team and information about how to lodge a complaint, a consent form, information about the procedure to be followed in specific situations, for example, if the interview reveals a previously undiagnosed medical or nursing problem. A tape-recording of this information can be made available to visually impaired residents.
- VII. After the participant has read the information and has had an opportunity to ask any questions about study Mrs O'Neill will inform potential participants that they have a one day cooling off period to decide if they wish to take part in the study.
- VIII. If this is agreeable with potential participants Mrs O'Neill will confirm by telephone date/time for the initial interview to take place in person's home or in hospital ward environment if person being admitted directly to care home. At the end of the interview, Mrs O'Neill will remind participants of their right to withdraw from the study if they feel that they have not had sufficient time to consider their involvement.
- IX. The researcher will obtain informed consent for each of the individual interviews in person. The participants will be informed that they can withdraw consent at any time.

The Research Team recognise that care homes within the independent and voluntary sector may currently have systems in place for approving and monitoring research. Consequently, the team will be guided by the manager/proprietor in relation to the process to be followed for gaining permission to carry out the study.

## Appendix 8: Cover Letter of Invitation



### Letter of Invitation

#### Title of Study

**Residents' experiences of moving from home into a care home.**

#### Dear Participant

You are being invited to take part in a study exploring the experiences of people who are moving into a care home. By taking part you have a chance to talk about your experiences of moving from home and living in a care home and how this impacts on your well-being. Your participation will involve taking part in a total of four one-to-one interviews (over the course of a year) at a time and place of your choosing.

This study aims to increase our understanding of how adults feel about moving from their own home to living in a care home over the course of a one year period.

The case manager/ care home manager who is assisting you with planning your move into a care home would like to ask your permission to pass on your contact details to us, so that we can contact you about the study. You do not have to decide today to take part, only that we can contact you.

***If you would prefer not to be contacted, this will not affect your care in any way.***

Thank you for taking the time to read this letter and for considering taking part in this research study.

Marie O'Neill Room MG207C Lecturer in Nursing Ulster University Magee Campus Londonderry BT48 7JL Tel: 028 71 675437 (direct line) E mail: m. <a href="mailto:oneill@ulster.ac.uk">oneill@ulster.ac.uk</a>	Professor Assumpta Ryan Room MG105 Chief Investigator Ulster University Magee Campus Londonderry BT48 7JL Tel: 028 71 675350 (direct line) Email: <a href="mailto:aa.ryan@ulster.ac.uk">aa.ryan@ulster.ac.uk</a>
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**Title of Study**

**Residents' experiences of moving from home into a care home.**

I confirm that I am giving permission for the researchers to contact me about taking part in this 'moving to a care home' study.

I understand that I am under no obligation to take part in the study.

The information below will only be used to contact me about this study and will be treated as confidential by the researchers.

Name
Signature
Address
Phone Number

Please return this completed page to your care manager who will store it securely for the research team.



## Appendix 9: Participant Information Sheet



### INFORMATION SHEET FOR PARTICIPANTS

#### Title of Study

#### **Residents' experiences of moving from home into a care home.**

#### **Dear Participant**

You are being invited to take part in a study exploring the experiences of people moving into a care home.

#### ***Why is this study being carried out?***

There is a lack of research about how people feel about moving into a care home. This study aims to increase our understanding of how adults feel about moving from their own home to living in a care home over the course of a one year period. This type of research has not been undertaken in care homes before in Northern Ireland. The study will be used to identify ways of helping people make this move and to lessen the anxiety that many people feel about the move.

**This research study has been reviewed and approved by the Health and Social Care Research Ethics Committee (A)**

#### ***What are we asking you to do?***

If you are interested in becoming involved in this study you will be asked to sign a consent form and take part in a total of four one-to-one interviews (over the course of a year) with the researcher which will be arranged at a time convenient to you initially in on your own home/hospital environment then within the care home. During these interviews, you will be asked about your experiences of moving into a care home.

The interviews should last for about one hour and with your permission, the interview will be recorded. This audio recording will be used to obtain an accurate record of the interviewer's questions and your responses. Should you agree to take part in the interview, you do not have to talk about anything that you do not wish to discuss. However, any information that you are prepared to share will greatly inform this study. You are also free to withdraw from the study at any time.

In addition, we would like to receive details about your health history and the medication that you are taking from your medical/nursing notes. This



will help us to have a more accurate picture of your health status during your transition to living in the care home. All information that is collected about you during the course of this study will be kept strictly confidential.

***What are the potential benefits and risks of taking part?***

Little is known about how people experience the transition to a care home in Northern Ireland. By taking part you have a chance to talk about your experiences of moving and living in a care home and how this impacts on your well-being. If you become tired during the interview, we can stop and continue another day. If you feel in any way distressed, we will, with your permission, arrange for you to receive support. However, if during the course of the interview, we find out that you or someone else is at risk of harm we will have to act on this information and share it with a health or social care professional.

***What will happen to the information that you give us?***

Everything that you talk about during the interview will be treated as private and confidential. Only the research team will know your name and personal details. All the information we collect will be kept anonymous and confidential and will be entered onto a computer which is password protected and stored in a locked room at Ulster University. The results will be reported but your name will not be used.

***How can you make a complaint?***

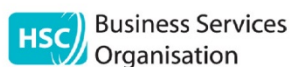
If you have any concerns about any aspect of the study, we would like to hear from you. You can contact Mr Nick Curry, Senior Administrative Officer at Ulster University (details below) who will make every attempt to resolve your concern or complaint. However, if you are still not happy your complaint will be addressed in accordance with the Ulster University's Complaints Procedures. Indemnity for the study has been secured through the Ulster Research governance processes. A copy of the letter confirming indemnity is available from us on request.

Mr Nick Curry  
Senior Administrative Officer  
Research & Innovation  
Room 26A17  
Ulster University  
Jordanstown campus  
Co. Antrim  
BT37 0QB  
Tel: 028 90366629 (direct line)  
Email: [n.curry@ulster.ac.uk](mailto:n.curry@ulster.ac.uk)

Thank you for taking the time to read this information sheet and for your interest in the study. **If you require any more information or if you have any questions or queries about the study, please do not hesitate to contact us at the following:**

Professor Assumpta Ryan Professor of Ageing and Health Room MG105 Chief Investigator Ulster University Magee Campus Londonderry BT48 7JL Tel: 028 71 675350 (direct line) Email: <a href="mailto:aa.ryan@ulster.ac.uk">aa.ryan@ulster.ac.uk</a>	Marie O'Neill Lecturer in Nursing Room MG207C Researcher Ulster University  Magee Campus Londonderry BT48 7JL Tel: 028 71 675437(direct line) E mail: <a href="mailto:m.oneill@ulster.ac.uk">m.oneill@ulster.ac.uk</a>
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## Appendix 10: ORECNI Amendment 1 REC Favourable Opinion



### Office for Research Ethics Committees Northern Ireland (ORECNI)

#### Customer Care & Performance Directorate

Unit 4, Lissue Industrial Estate West  
Rathdown Walk  
Moir Road  
Lisburn  
BT28 2RF  
Tel: 028 95361400  
[www.orecni.hscni.net](http://www.orecni.hscni.net)

**HSC REC A**

22 March 2017

Professor Assumpta Ryan  
Ulster University  
School of Nursing Magee Campus,  
Northland Road L/Derry  
BT48 7JL

Dear Professor Ryan

**Study title:** Residents' experiences of moving from home into a care home.  
**REC reference:** 16/NI/0167  
**Amendment number:** Amendment 1, 23/02/2017  
**Amendment date:** 27 February 2017  
**IRAS project ID:** 194418

The above amendment was reviewed at the meeting of the Sub-Committee held on 21 March 2017 in correspondence.

#### Ethical opinion

The amendment proposes to reduce the cooling off period for prospective participants to one day rather than 1 week. This is because there is now only a 2-3-day period before funding has been granted by the Western HSC Trust and patients are admitted to a care home. This has repercussions as the first interview needs to be undertaken before admission to a care home.

The members of the Committee taking part in the review gave a **favourable ethical opinion** of the amendment on the basis described in the notice of amendment form and supporting documentation.

#### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMP)	Amendment 1, 23/02/2017	27 February 2017
Other [Table of Document Changes]		
Other [Appendix 4, Guidance on the approach to case managers/care home managers.]	5	23 February 2017
Other [Appendix 5, Letter to Case Managers Intermediate and Acute Care Services WHSCT]	5	23 February 2017

*Providing Support to Health and Social Care*



Research protocol or project proposal	5	23 February 2017
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#### **Membership of the Committee**

The members of the Committee who took part in the review are listed on the attached sheet.

#### **Working with NHS Care Organisations**

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

#### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

<b>16/NI/0167:</b>	<b>Please quote this number on all correspondence</b>
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Yours sincerely

pp Dr Catherine Hack  
Chair  
E-mail: [RECA@hscni.net](mailto:RECA@hscni.net)

*Enclosures: List of names and professions of members who took part in the review*

*Copy to: Ms Sally Doherty, Western Health and Social Care Trust  
Mr Nick Curry, Ulster University*

**HSC REC A****Attendance at Sub-Committee of the REC meeting on 22 March 2017****Committee Members:**

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr Catherine Hack	Consultant in Academic Practice (STEM)	Yes	Chair
Dr Toni McAloon	Nurse Lecturer	Yes	

**Also in attendance:**

<i>Name</i>	<i>Position (or reason for attending)</i>
Miss Kathryn Taylor	REC Manager

## Appendix 11: Ulster University Approval RG3 O'Neill /Ryan

UNIVERSITY OF ULSTER	RESEARCH GOVERNANCE
<b>RG3 Filter Committee Report Form</b>	
Project Title	Residents' experiences of moving from home into a care home.
Chief Investigator	Professor Assumpta Ryan
Filter Committee	Nursing and Life Sciences

This form should be completed by Filter Committees for all research project applications in categories A to D (\*for categories A, B, and D the University's own application form – RG1a and RG1b – will have been submitted; for category C, the national, or ORECNI, application form will have been submitted).

Where substantial changes are required the Filter Committee should return an application to the Chief Investigator for clarification/amendment; the Filter Committee can reject an application if it is thought to be unethical, inappropriate, incomplete or not valid/viable.

**Only when satisfied that its requirements have been met in full and any amendments are complete, the Filter Committee should make one of the following recommendations:**

The research proposal is complete, of an appropriate standard and is in

- category A and the study may proceed\* ☐
- category B and the study must be submitted to the University's Research Ethics Committee\*\* Please indicate briefly the reason(s) for this categorisation ☐
- category C and the study must be submitted to ORECNI along with the necessary supporting materials from the Research Governance Section\*\*\* ☒
- category D and the study must be submitted to the University's Research Ethics Committee\*\* ☐

Signed: <i>George Kernohan</i> Chairperson of Filter Committee	Date: 22-Mar-16
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\*The application form and this assessment should now be returned to the Chief Investigator. The Filter Committee should retain a copy of the complete set of forms.

\*\* The application form and this assessment should now be returned to the Chief Investigator so that he/she can submit the application to the UUREC via the Research Governance section. The Filter Committee should retain a copy of the complete set of forms for their own records.

\*\*\* The application form and this assessment should now be returned to the Chief Investigator so that he/she can prepare for application to a NRES/ORECNI committee. The Filter Committee should retain a copy of the complete set of forms for their own records.

For all categories, details of the application and review outcome should be minuted using the agreed format and forwarded to the Research Governance section

**Please complete the following**

The application should be accompanied by an appropriate and favourable Peer Review Report Form (if not, the Filter Committee should be prepared to address this as part of its review). Please comment on the peer review (include whether or not there is evidence that the comments of the peer reviewers have been addressed).

Peer review was completed by Dr Stinson and Dr Keeney and there are no outstanding issues of serious ethical concern.

Please provide an assessment of all component parts of the application, including questionnaires, interview schedules or outline areas for group discussion/unstructured interviews.

The study comprises of semi-structured interviews and is planned for WHSCT with approximately 15-20 older people to explore residents' experiences of moving from home to a care facility over a one year period. The HRA committee may wish to see copy of the MMSE instrument.

Please comment on the consent form and information sheet, in particular the level of language and accessibility.

Researcher a PIS and consent form has provided. The PIS conforms to necessary standard and includes all pertinent information. It is common to include contact information for Complaints Procedure (via N Curry's Office). As ongoing consent will be obtained on three occasions – this will need to be recorded.

Please comment on the qualifications of the Chief and other Investigators.

The qualifications of the Chief Investigator are appropriate. CVs have been included for all research team members.

Please comment on the risks present in conducting the study and whether or not they have been addressed.

No serious risks have been identified. All efforts have been made to address any potential risks.

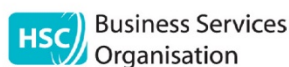
Please indicate whether or not the ethical issues have been identified and addressed.

Ethical issues around consent, confidentiality, distress protocol and lone worker protocols have all been discussed and addressed.

Please comment on whether or not the subjects are appropriate to the study and the inclusion/exclusion criteria have been identified and listed

Study sample is appropriate given the research question being addressed. Clear inclusion/exclusion criteria have been reported on the RG1 form. Study will include very elderly participants– with justification provided that a minimum cognitive impairment value of (>24) will be applied according to MMSE. Inclusion/Exclusion criteria seem appropriate given the nature of the study. Some people with specific major illnesses or disabilities are being excluded.

## Appendix 12: ORECNI REC Favourable Opinion



### Office for Research Ethics Committees Northern Ireland (ORECNI)

#### Customer Care & Performance Directorate

Unit 4, Lissue Industrial Estate West  
Rathdown Walk  
Moir Road  
Lisburn  
BT28 2RF  
Tel: 028 95361400  
[www.orecni.hscni.net](http://www.orecni.hscni.net)  
**HSC REC A**

26 September 2016

Professor Assumpta Ryan  
Ulster University  
School of Nursing Magee Campus,  
Northland Road, L/Derry  
BT48 7JL

Dear Professor Ryan

**Study title:** Residents' experiences of moving from home into a care home.  
**REC reference:** 16/NI/0167  
**IRAS project ID:** 194418

Thank you for your letter of 23 September 2016, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair and the Lead Reviewer for the application, Mrs Celia Diver-Hall.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Kathryn Taylor, [RECA@hscni.net](mailto:RECA@hscni.net).

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a **favourable ethical opinion** for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

*Providing Support to Health and Social Care*





*Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).*

*Guidance on applying for NHS permission for research is available in the Integrated Research Application System, [www.hra.nhs.uk](http://www.hra.nhs.uk) or at <http://www.rdforum.nhs.uk>.*

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of management permissions from host organisations*

#### **Registration of Clinical Trials**

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett ([catherineblewett@nhs.net](mailto:catherineblewett@nhs.net)), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### **Ethical review of research sites**

##### **NHS sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### **Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Letters of invitation]	4	25 March 2016
Covering letter on headed paper		21 September 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Letter of Indemnity]		07 July 2016
Interview schedules or topic guides for participants [Topic Guide]	1	26 October 2015
IRAS Checklist XML [Checklist_26072016]		26 July 2016

IRAS Checklist XML [Checklist_23092016]		23 September 2016
Letter from sponsor [Sponsor Letter]		07 July 2016
Letters of invitation to participant [Letter of Invitation]	4	25 March 2016
Other [Lone Worker Protocol]	1	26 February 2016
Other [Disclosure Protocol]	1	26 February 2016
Other [Guidance to Case Managers]	4	21 September 2016
Other [Letter to Case Manager]	4	21 September 2016
Other [Distress Protocol]	3	08 September 2016
Other [ORECNI Comments]		21 September 2016
Participant consent form [CONSENT]	4	25 March 2016
Participant information sheet (PIS) [PIS]	5	21 September 2016
REC Application Form [REC_Form_26072016]		26 July 2016
Research protocol or project proposal [RG3 Filter Committee Report]		22 March 2016
Research protocol or project proposal [Research Proposal]	4	21 September 2016
Summary CV for Chief Investigator (CI) [Prof Ryan CV]		
Summary CV for student [CV MON]	Version 1	03 February 2016
Summary CV for supervisor (student research) [CV Supervisor SON]	Version 1	03 February 2016

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### After ethical review

##### Reporting requirements

The attached document “*After ethical review – guidance for researchers*” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

#### HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

16/NI/0167	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely



pp Dr Catherine Hack  
Chair  
Email: [RECA@hscni.net](mailto:RECA@hscni.net)

*Enclosures:* "After ethical review – guidance for researchers"

*Copy to:* Mr Nick Curry, Ulster University  
Ms Sally Doherty, Western Health and Social Care Trust

## Appendix 13: WHSCT Research study approval



26 October 2016

Professor Assumpta Ryan  
Ulster University  
School of Nursing Magee Campus  
Northland Road  
Londonderry BT48 7JL

Dear Professor Ryan

**Study Title:** Residents' experiences of moving from home into a care home

**HSC Trust Ref:** WT 16/22 (Please quote this number in all future correspondence)

**IRAS Ref:** 194418

**REC Ref:** 16/NI/0167

I am pleased to advise that WHSCT has given Final Research Governance Permission for the above project to commence. Permission is granted for the duration of the project to 16/06/21.

The following documents have been approved for use in the project:

Document	Version	Date
Research protocol	4	21/09/2016
Appendix 1 Interview Topic Guide	1	26/10/2015
Appendix 2 Participant Information Sheet	5	21/09/2016
Appendix 3 Consent Form	4	25/03/2016
Appendix 4 Guidance on the approach to case managers nursing home managers	4	21/09/2016
Appendix 5 Letter to Case Managers	4	21/09/2016
Appendix 6 letter of Invitation	4	25/03/2016
Appendix 7 Lone Worker Protocol for Researcher	1	26/02/2016
Appendix 8 Distress Protocol for Researcher	2	26/02/2016

Research & Development Office, C-TRIC, Altnagelvin Area Hospital,  
Londonderry BT47 6SB  
DDI 02871 611156  
02871 345171 EXT 216603/4



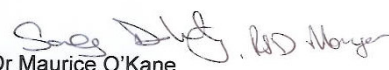
The following personnel have been approved to work on the study at this Trust:

Name	Indemnity Provided by
Ms Deirdre Walker	WHSCT
Ms Marie O'Neill	Ulster University

Permission is granted subject to the attached conditions and I would ask you to please ensure that all members of the research team are familiar with these. Failure to abide by these conditions will invalidate permission and may result in the cessation of the research.

I wish you every success with your project.

Yours sincerely

  
 Dr Maurice O'Kane  
 Director of Research & Development

Cc Ms Deirdre Walker, Assistant Director, Adult Safeguarding (via e mail)

Research & Development Office, C-TRIC, Altnagelvin Area Hospital,  
 Londonderry BT47 6SB  
 DDI 02871 611156  
 02871 345171 EXT 216603/4



#### **Conditions of Permission**

Research Governance permission is issued provided the researcher(s) involved adhere to and abide by the conditions below.

- The researcher(s) must adhere strictly to the research protocol.
- There must be no changes to the research protocol or approved study documentation without the prior consent of the Trust, the Research Ethics Committee and, where applicable, the MHRA.
- There must be no changes in research staff without prior consent of the Trust.
- The Research Office should be informed if the Chief Investigator or Principal Investigator(CI/PI) is unable to continue to fulfil his/her duties as CI/PI for any reason such as long term absence, change in employment etc.
- There must be no increase in the resources required without prior consent of the Trust.
- Researcher(s) must report all untoward incidents and serious adverse events to the Trust.
- Any concerns in relation to the research protocol must be reported to the Trust.
- Researcher(s) must adhere to good research practice principles in line with the ICH Good Clinical Practice (GCP) guidelines.
- Researcher(s) must adhere to the Trust's Research & Development Standard Operating Procedures (available from the Research Office on request)
- On request, researcher(s) must make their research project available to Trust appointed monitors.
- The lead researcher must make an annual report to the Research Office for the duration of the project.
- The lead researcher should inform the Research Office on completion or termination of the project. Completion reports must be sent to the Research Office, Research Ethics Committee and, if applicable, MHRA.

**Research & Development Office, C-TRIC, Altnagelvin Area Hospital,  
Londonderry BT47 6SB  
DDI 02871 611156  
02871 345171 EXT 216603/4**

## Appendix 14: Distress Protocol



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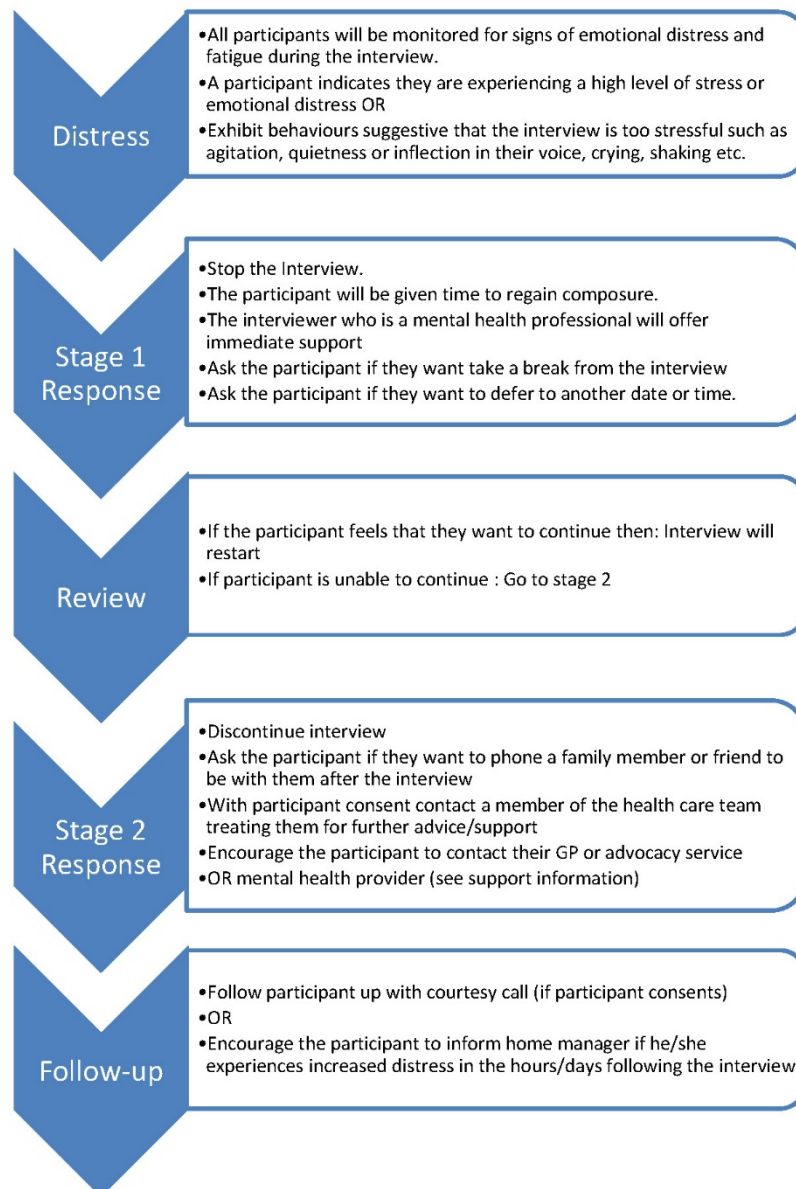
### **Distress Protocol for Researcher**

ULSTER UNIVERSITY

Chief Investigator: Professor Assumpta Ryan

Researcher: Marie O'Neill





**Distress Protocol 1:** The protocol for managing distress in the context of an interview  
 (Modified from : Draucker, C. B., Martsof, D. S., and Poole, C. (2009) Developing Distress Protocols for research on Sensitive Topics. *Archives of Psychiatric Nursing*, 23 (5) pp 343-350).



## Residents' experiences of moving from home into a care home.

### Support Information for Participants:

You are participating in a research study exploring the experiences of people moving into a care home.

We welcome your contribution to this study. A range of support is available to you in relation to this study

**For queries and/or concerns about the conduct of this study, contact:**

Assumpta Ryan Professor of Ageing and Health Ulster University Northland Rd Derry/ Londonderry BT48 7JL T 02871675350 Email: <a href="mailto:aa.ryan@ulster.ac.uk">aa.ryan@ulster.ac.uk</a>	Marie O'Neill Lecturer in Nursing Ulster University Northland Rd Derry/ Londonderry BT48 7JL T 02871675437 E mail: <a href="mailto:m.oneill@ulster.ac.uk">m.oneill@ulster.ac.uk</a>
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For queries and/or concerns about experiencing anxiety or lowered mood, you may wish to contact one or the following:

<b>Your GP</b>  <b>Your Nurse</b>  <b>Your Social Worker</b>	Age NI Advice & Advocacy Service  T: 0808 808 7575  <a href="http://www.ageuk.org.uk/northern-ireland">www.ageuk.org.uk/northern-ireland</a>	Psychological services are available for people experiencing emotional distress via G.P or CMHT referral.  <b>Community Mental Health Teams (CMHT)</b>  Cityside/Strabane CMHT, T: 028 7186 4384 Waterside/Limavady CMHT, T: 028 7186 4384 West Tyrone CMHT, T: 028 8223 5993 Fermanagh CMHT, T:028 6634 4048  <b>Older Adult Clinical Psychology Service</b> Oak Villa, Gransha Park Derry Tel: 028 71 865114 Holly Villa, Tyrone and Fermanagh Hospital, Omagh Tel: 028 8283 5996
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## Appendix 15: Disclosure Protocol for Researcher



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### Disclosure Protocol for Researcher

ULSTER UNIVERSITY

2016/18

WHISTLEBLOWING

(PUBLIC INTEREST DISCLOSURE)

POLICY

Chief Investigator: Professor Assumpta Ryan

Researcher: Marie O'Neill

### **Disclosure Protocol for Individual Interviews Protocol:**

All research undertaken in a care home needs to anticipate how the researcher will work with care home staff and have agreed protocols if problems arise (e.g. if bad practice is observed, or research study findings highlight problems or if staff or residents identify areas of concern).

The Nursing and Midwifery Council (NMC) website provides useful information on safeguarding resources and best practice to nurses within Northern Ireland including relevant legislation from Department of Health, Social Services and Public Safety (2015). In addition the NMC provide professional guidance for rising and escalating concerns in areas such as; issues to do with staff conduct, such as unprofessional attitudes or behaviour, including concerns related to equality and diversity.

During interviews participants may disclose personal experiences that may reveal unprofessional practice. The researcher has a duty of care to report these disclosures to the appropriate persons. Participants will be informed of these risks from disclosure of this type of information prior to interview. A protocol for distressed participants has been designed (see appendix)

The researcher will follow the Ulster University Code of Practice for Professional Integrity in the Conduct of Research as well as the Ulster University Whistleblowing (public interest Disclosure) Policy.

In addition the researcher will follow the Western Health and Social Care Policy and procedures on adult safeguarding.

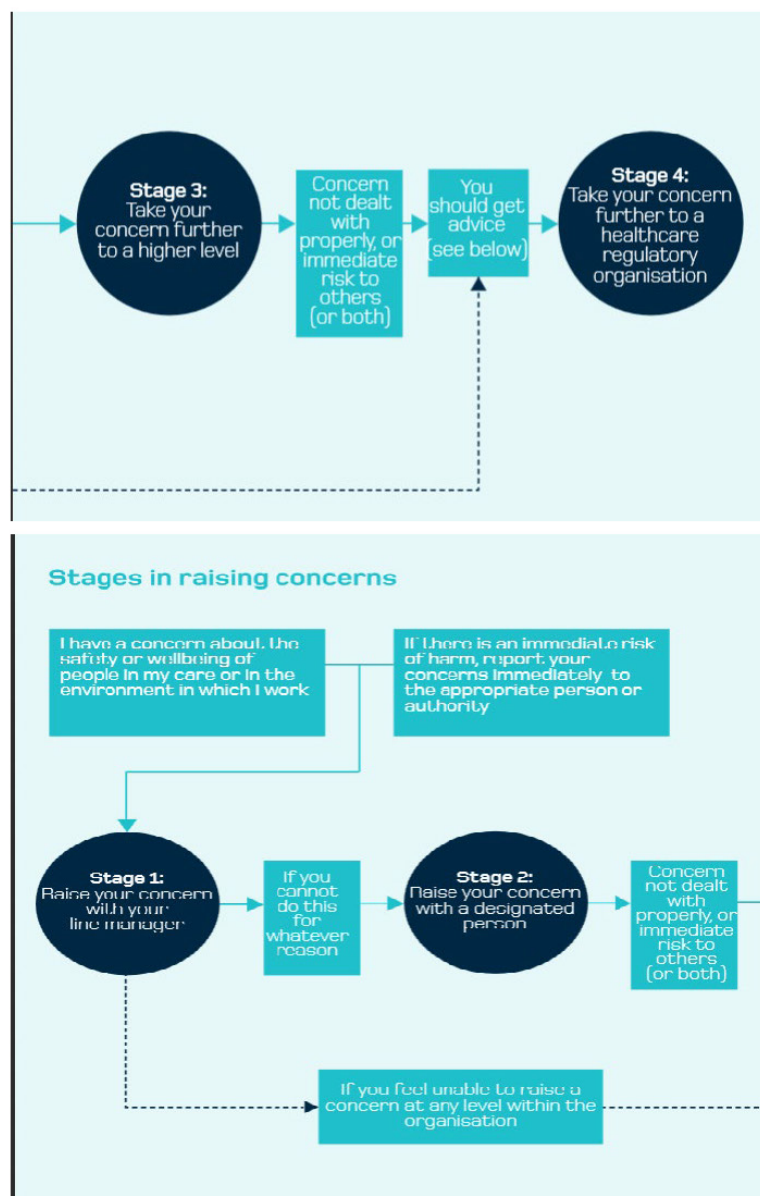
Accurate records of the discussions will be completed.

#### **Stage one:**

Issue will be discussed with the Chief investigator Professor Assumpta Ryan on Tel: 02871675350 or email: AA.Ryan@ulster.ac.uk

#### **Stage two:**

Appropriate discussions will take place initially with case managers/care home managers or relevant individuals within Care Home. Thereafter if deemed necessary as protocol directs discussions will take place with clinical partners in Western Health and Social Care Trust including governance departments in the Trust and Ulster University



## Appendix 16: Consent Forms



### Consent Form ONE

#### (Interview ONE Pre-Residence Interview)

#### Title of study

Residents' experiences of moving from home into a care home.

#### Name of Researchers:

Chief Investigator: Professor Assumpta Ryan

Research Officer: Marie O'Neill

#### Please tick box

I confirm that I have been given and have read and understood the information sheet for this study. I have been able to speak to the research team to get any queries or concerns clarified. [ ]

I understand that my participation is voluntary and I am free to withdraw at any time without giving a reason and without my rights being affected in any way. [ ]

I give permission for the researchers to obtain information about my health history and current medication from the case manager/ care home manager. [ ]

I understand that the researchers will hold all information and data collected securely and in confidence and that all efforts will be made to ensure that I cannot be identified as a participant in the study. [ ]

I agree to take part in the above study and to have my answers recorded on a digital recorder. [ ]

I agree to quotation/publication of extracts from my Interview [ ]

<b>Your Name:</b>	<b>Date:</b>
<b>Signature:</b>	
<b>Researcher Name</b>	<b>Date</b>



**Consent Form TWO**  
(Interview TWO 4-6 weeks)

**Title of study**  
Residents' experiences of moving from home into a care home.

**Name of Researchers:**

Chief Investigator: Professor Assumpta Ryan

Research Officer: Marie O'Neill

**Please tick box**

I confirm that I have been given and have read and understood the information sheet for this study. I have been able to speak to the research team to get any queries or concerns clarified. [ ]

I understand that my participation is voluntary and I am free to withdraw at any time without giving a reason and without my rights being affected in any way. [ ]

I give permission for the researchers to obtain information about my health history and current medication from the care home manager. [ ]

I understand that the researchers will hold all information and data collected securely and in confidence and that all efforts will be made to ensure that I cannot be identified as a participant in the study. [ ]

I agree to take part in the above study and to have my answers recorded on a digital recorder. [ ]

I agree to quotation/publication of extracts from my Interview [ ]

<b>Your Name:</b>	<b>Date:</b>
<b>Signature:</b>	
<b>Researcher Name</b>	<b>Date</b>



### Consent Form THREE

(Interview THREE 4-5 months)

#### Title of study

Residents' experiences of moving from home into a care home.

#### Name of Researchers:

Chief Investigator: Professor Assumpta Ryan

Research Officer: Marie O'Neill

#### Please tick box

I confirm that I have been given and have read and understood the information sheet for this study. I have been able to speak to the research team to get any queries or concerns clarified. ☐

I understand that my participation is voluntary and I am free to withdraw at any time without giving a reason and without my rights being affected in any way. ☐

I give permission for the researchers to obtain information about my health history and current medication from the care home manager. ☐

I understand that the researchers will hold all information and data collected securely and in confidence and that all efforts will be made to ensure that I cannot be identified as a participant in the study. ☐

I agree to take part in the above study and to have my answers recorded on a digital recorder. ☐

I agree to quotation/publication of extracts from my Interview ☐

<b>Your Name:</b>	<b>Date:</b>
<b>Signature:</b>	
<b>Researcher Name</b>	<b>Date</b>



**Consent Form FOUR**  
**(Interview FOUR 9-12 months)**

**Title of study**

Residents' experiences of moving from home into a care home.

**Name of Researchers:**

Chief Investigator: Professor Assumpta Ryan

Research Officer: Marie O'Neill

**Please tick box**

I confirm that I have been given and have read and understood the information sheet for this study. I have been able to speak to the research team to get any queries or concerns clarified. [ ]

I understand that my participation is voluntary and I am free to withdraw at any time without giving a reason and without my rights being affected in any way. [ ]

I give permission for the researchers to obtain information about my health history and current medication from the care home manager. [ ]

I understand that the researchers will hold all information and data collected securely and in confidence and that all efforts will be made to ensure that I cannot be identified as a participant in the study. [ ]

I agree to take part in the above study and to have my answers recorded on a digital recorder. [ ]

I agree to quotation/publication of extracts from my Interview [ ]

<b>Your Name:</b>	<b>Date:</b>
<b>Signature:</b>	
<b>Researcher Name</b>	<b>Date</b>



## Appendix 17: Coding Exemplars

Causal Conditions: Deterioration in Health			
Narrative Exemplars	Concepts	Subcategories	Categories
<p><i>"Well I had a stroke you see, and I was in Hospital for 8 weeks and I was not able to go home after that I had to come here. (Therese)</i></p> <p><i>"I have really bad arthritis now and I would have bother getting about you know. You feel as you get older everything starts to fail...it gets worse" (Jane)</i></p> <p><i>"Well I had sicknesses, two operations on my hip, and that's why I can't walk very well, and I had this thing with falling. The doctor said it comes from the heart and they put a loop in but it still doesn't help with the falling so I fell 3 weeks ago and I couldn't get up, so I pressed emergency button and they came and took me to XXXXX Hospital" (Ellen)</i></p> <p><i>"My health started to deteriorate, and I am coming to an age where I can't be sure of my health anymore" (David)</i></p> <p><i>"Well I had a bad fall a few months ago and I wasn't really myself after that. I lost my confidence and of course they worried away about me and wanted to make sure nothing happened to me" (Tracey)</i></p>	<p>Precipitating event</p> <p>Failing Health</p> <p>Emerging Health Needs</p> <p>Needing help</p> <p>Awareness of Capabilities</p> <p>Loss of Confidence</p> <p>Family concern</p>	<p>Health Decline</p> <p>Health Uncertainties</p> <p>Health concerns</p>	<p><b>Deterioration in Health</b></p>

Causal Conditions: Changes in Social Circumstances			
Narrative Exemplars	Concepts	Subcategories	Categories
<p><i>"I came into the home because I had to go to Hospital the day my wife took sick, she died in hospital" (Charles)</i></p> <p><i>"Well my brother died .... I had been living with them.... My brother had left instructions that I was to be looked after.... but it didn't work out like that. How would you like to be put in a home against your will? (Sophie)</i></p> <p><i>"Well I live on my own and the family think it is a good thing that I should move into the nursing home as they are all going to be away now and there is no one here to look after me.....Well the family arranged all this..... I wouldn't know what to do about getting it sorted "(Martina)</i></p> <p><i>"My daughter and I were living together, and my daughter fell on the doorway, on the step. She was my carer and now she has broken her back in three places, and she won't be able to take care of me anymore" (Mona)</i></p> <p><i>Well my son thinks that moving in here would be better for helping me to bath myself. He goes away a lot now, not on holidays but to work. He worries about me you know in case I would fall, and he was away (Isobel).</i></p>	<p>No choice</p> <p>Loss</p> <p>Underlying family dynamics</p> <p>Family involvement</p> <p>Loss of carer input</p> <p>Help with care needs.</p> <p>Family concern</p>	<p>Loss of Family</p> <p>Changing Family Circumstances</p>	<p>Changes in Social Circumstances</p>

Causal Conditions: Increased Vulnerability to Living Alone			
Narrative Exemplars	Concepts	Subcategories	Categories
<p><i>"The problem with the mini strokes is you don't know where or when you know and so I forget about those. What's the use of thinking about those all the time? Whatever will be will be? I'm 89 now and I realise I couldn't go back to the house because I would be 90 in June and I would be starting again at 90 which is just too late you know" (Anne)</i></p> <p><i>"I did everything when I was able. We had a golden retriever dog and I walked it every day and we had to get her put down because she had cancer and we never got another dog. I loved my walk, and I went every Thursday morning to have my coffee with neighbours but that's all gone now" (Martha)</i></p> <p><i>"Well I had a bad fall a few months ago and I wasn't really myself after that. I lost my confidence and of course they worried away about me and wanted to make sure nothing happened to me" (Martina)</i></p> <p><i>"Well I have that problem of losing my balance.... Yeah, and also now I had to give up driving and that's a big disadvantage in the country "(Joseph)</i></p>	<p>Awareness of capability</p> <p>Changing abilities</p> <p>Loss of confidence</p> <p>Loss of independence</p>	<p>Deterioration in Health</p> <p>Precipitating Events</p>	<p><b>Increased Vulnerability to Living Alone</b></p>

Contextual and Intervening Conditions: Experience of Hospital Care			
Narrative Exemplars	Concepts	Subcategories	Categories
<p><i>"Everything is different, everything. The hospital staff have taken really good care of me. So, I hope I like it here, and the care staff are nice. It took me a long time to get here" (Ellen)</i></p> <p><i>One day I fell at the front door. I felt my head was spinning, I couldn't get up, and my son got the ambulance. They did all the tests when they took me to the hospital, they thought there was something wrong with my brain, but they couldn't find anything. That's why they sent me here. .... but it took a long time to try and get a diagnosis" (David)</i></p> <p><i>I had an MRI scan...they didn't tell me what the result was but later ... well it was in xx hospital before they told me that it was a clot that caused it the stroke. Then I was put on Aspirin... not on too much I suppose. There was a doctor on the ward... (laughs) he said are you driving? I said yes. He said don't drive for a month then. Imagine I can't even hold my arm or walk" (Therese)</i></p> <p><i>"I haven't walked since I fell at home. I'm supposed to be getting occupational therapy before I go off to the home, but I haven't been getting any help yet".</i></p>	<p>Changing circumstances</p> <p>Hopeful anticipation.</p> <p>Finding a diagnosis</p> <p>Investigating source of problem</p> <p>Impractical predictions</p> <p>Preparations not fulfilled.</p>	<p>Health care provision</p>	<p>Experience of Hospital Care</p>

Contextual and Intervening Conditions: Abrupt Departures- Thoughts about Leaving Home			
Narrative Exemplars	Concepts	Subcategories	Categories
<p><i>"Look love I am here now, I've arrived. There is no going back home. I have to put up with it so there is no point in me talking about it anymore. I just need to get on with it now". I don't want to talk about it" (Martina)</i></p> <p><i>"I don't care, .....it's all right, what can you do," (Bernadette)</i></p> <p><i>"When I was told I had to come here, someone out of the family had to come and get me at the hospital. They came and we packed and that's how it was". (Anne)</i></p> <p><i>"They just told me that they were sending me to a nursing home. I just came here and checked in." (Charles)</i></p> <p><i>"I'm lost, what'll I do. I have nobody and this is the end. I am ill" (Sarah)</i></p> <p><i>"I can't explain how I feel.....It's the feeling inside.... Terrible" (Ellen)</i></p> <p><i>"I have a strong mind, but it was a big thing to give up the house and for us to be separated" (Martha)</i></p>	<p>Resignation</p> <p>Being submissive</p> <p>Following the process</p> <p>Under instruction</p> <p>Despair</p> <p>Foreboding</p> <p>Reflection on self</p>	<p>Thoughts about the Move</p> <p>Health service provision direction</p> <p>Emotional responses</p>	<p><b>Abrupt Departures- Thoughts about Leaving Home</b></p>

Contextual and Intervening Conditions: Support with the Move			
Narrative Exemplars	Concepts	Subcategories	Categories
<p><i>"Some of the nieces will come with me or my nephews, and then we are sorting all sorts at home. First of all, I'm sorting the papers to the house out ..... there's a collection of papers sitting there. I have time up here to do it, so one of them brought my case up with all the papers in it so I'm sorting those out at the moment you know" (Anne)</i></p> <p><i>"I have one good neighbour and after my husband died, he did a lot for me... you know when somebody dies, the paperwork, oh God! It's shocking what you have to do and remember. They helped me to move here and are going to help me get the things sorted in the house" (Ellen)</i></p> <p><i>"I will have to get home to get the bills sorted ...like I have to get the grass cut and get someone to look after things at home." (Andrew)</i></p> <p><i>"It's sheltered housing so not so bad. My sister is up there now sorting the last of the things out" (Molly).</i></p>	<p>Managing affairs</p> <p>Help and assistance</p> <p>Planning help</p> <p>Settling things</p>	<p>Ongoing support to manage affairs</p> <p>Getting matters finalised to move on</p>	<p><b>Support with the Move</b></p>

Actions/Interactions: Endorsement by Health and Social Care Practitioners			
Narrative Exemplars	Concepts	Subcategories	Categories
<p><i>"I didn't know much about that nursing home ...the social worker chose where I should go. When I came around to saying to the social worker that the home wasn't for me, she agreed this residential home was more suitable" (Anne)</i></p> <p><i>"It's a very nice room...the nurses say I can make it more homely, more like home. I can be happy in it you know" (Isobel)</i></p> <p><i>"I came here with nothing but the clothes I was standing in.....no shoes nothing...the social worker says I had to come" (Charles)</i></p> <p><i>"The social worker wanted to know when I would get my stuff, but she wouldn't give me a time. She wanted to know when I was giving up the flat" (Sarah)</i></p> <p><i>"The doctors said it was best and I wanted to come in here. I was frightened living on my own". (Molly)</i></p> <p><i>The social workers make all the decisions. So really you are at the mercy of other people and the health care system, aren't you? (Sean)</i></p>	<p>Plans being made for me</p> <p>Realisation</p> <p>Optimism</p> <p>Moving in haste</p> <p>Feeling ignored</p> <p>Feeling afraid</p> <p>At the Mercy</p>	<p>Support</p> <p>Assurance</p> <p>Decision Making</p>	<p><b>Endorsement by Health and Social Care Practitioners</b></p>

Actions/Interactions: Decision Making and Choice of Care Home			
Narrative Exemplars	Concepts	Subcategories	Categories
<p><i>"I chose this nursing home. My wife is here, and I liked what I saw here, (David)</i></p> <p><i>"My daughter chose this nursing home. She went looking around all the nursing homes and then decided on this one" (Andrew)</i></p> <p><i>"It was the family. I just had to do what they say. I did it because I knew what was going to happen...." (Bernadette)</i></p> <p><i>"The doctor said I needed to come in here. What can I do, I have no choice? I couldn't go home unless I was fit or had proper care at home. There was a bed vacant here but somebody else took the bed and I had to wait until they got another for me here" (Therese)</i></p> <p><i>"Sorry (tearful), I came here because there was nowhere for me to go" (Sean)</i></p> <p><i>"You don't have much choice, most of them are full, that's the problem, and this was the only one I could get." (Ellen)</i></p> <p><i>"My family chose this home. This is the nearest one to the home place, so I suppose it was a reasonable choice" (Joseph)</i></p>	<p>Family Choice</p> <p>Availability</p> <p>Resignation</p> <p>Inevitability</p> <p>No choice</p> <p>Understanding</p>	<p>Options</p> <p>Difficult decisions</p>	<p>Decision Making and Choice of Care Home</p>



Actions/Interactions: Making the Move			
Narrative Exemplars	Concepts	Subcategories	Categories
<p><i>"They just told me that they were sending me to a nursing home. I just came here and checked in. I had nothing at all with me, nothing. Not even a change of clothes" (Charles)</i></p> <p><i>"Well the people...the carers from the home came and got me from the hospital" (James)</i></p> <p><i>"It was a big thing to give up the house and for us to be separated. My sister in law wasn't a bit happy either, we got her talked into going into the other home" (Martha).</i></p> <p><i>When the bed becomes available well that's it, apparently you have to grab it. The sad thing for me about moving to the care home tomorrow is that I'm walking in a dead man's shoes! (David)</i></p> <p><i>I had to come here because there are no other homes available for someone of my age.... So really you are at the mercy of other people and the health care system, aren't you? (Sean)</i></p>	<p>Abrupt departure</p> <p>Arrangements made</p> <p>Separation</p> <p>Window of opportunity</p> <p>Meeting service needs</p>	<p>Management of the move</p> <p>Available choices</p>	<p><b>Making the Move</b></p>

Consequences: Maintaining Identity			
Narrative Exemplars	Concepts	Subcategories	Categories
<p><i>"I wouldn't feel like myself here. The farm is my life so that is where I want to be every day. You never retire being a farmer you know it is in your blood ..... a way of living" (Joseph)</i></p> <p><i>"I like to be sort of my own person, but I go down and chat with them if they're there in the dayroom. Most of them are. I chat away to them and share the papers with them. Och aye I do like to mix with them too not to be individual or anything like that" (Anne)</i></p> <p><i>"I think that I'm getting too old to do anything now, I just like having my family coming to visit" (Jane)</i></p> <p><i>"My next door neighbour is in here. He had his legs amputated. And I know him better now than I knew him before. He's a very intelligent man. We sit and chat every day (James)</i></p> <p><i>"I try and help them you know the other people if they have any worries or to hear their story. And all that sort of thing but you know I'm quite happy here. At the beginning I was nervous but not now, no.... not anymore" (Tracey)</i></p>	<p>This is me</p> <p>My own Person</p> <p>Realisation of what I want</p> <p>Finding Friendship</p> <p>Finding my place</p>	<p>Reflections on Self</p> <p>Being myself</p>	<p><b>Maintaining Identity</b></p>

Consequences: Holding on to Self.			
Narrative Exemplars	Concepts	Subcategories	Categories
<p><i>"I was content where I was. I did not want to move into any home. I don't belong here..... It's not for me "(Sophie)</i></p> <p><i>"It's a very sad time for me you know.... So, I don't know whether I'm right or wrong staying quiet" (Tracey)</i></p> <p><i>"I couldn't sit in a big room with a whole lot of people looking at TV all day. I didn't want to be like that or turn into something that I wasn't. And even in that big room the poor souls would all fall asleep. And I thought you know I'm just not suited to this at all" (Anne)</i></p> <p><i>So many in here are here for life, it's like a wee village (laughter). The older people are resident's I see myself as a patient.... (Sean).</i></p> <p><i>"The future.....you don't have much choice being in here but I'm holding on" (Andrew)</i></p>	<p>Resistance</p> <p>Feeling lost</p> <p>Keeping me</p> <p>disassociation</p> <p>Holding on</p>	<p>Disconnected</p> <p>Fortitude</p>	<p><b>Holding on to Self.</b></p>

Consequences: Connections to Home and Family			
Narrative Exemplars	Concepts	Subcategories	Categories
<p><i>"My wife will come in every day; we have been doing that since I first went into hospital" (Sean)</i></p> <p><i>"You would be glad to see someone coming in to see you. My sister will be coming in tomorrow" (Molly)</i></p> <p><i>"My sister comes far too often (laughs) she came every day when I was in Hospital ... far too much but you couldn't tell her.... she told me she cried when she saw me "(Therese)</i></p> <p><i>"My family come in all that time and that makes a difference" (Joseph)</i></p> <p><i>"There's not much to look forward to now I'm here. I mean I look forward to seeing people belonging to me coming in" (Isobel)</i></p> <p><i>"I'm too old to be thinking of things. I like peace and I like my family to be near" (Jane)</i></p> <p><i>"I've got nobody, no family" (Sarah)</i></p> <p><i>"They have told me that when they come over to visit, they will take me out home and to my wife's grave "(Andrew)</i></p>	<p>Keeping routine</p> <p>Appreciation of visitors</p> <p>Family connections</p> <p>Making a difference</p> <p>Anticipation of family visits</p> <p>Prioritising what's important</p> <p>Being alone</p> <p>Looking forward</p>	<p>Importance of Family</p> <p>Maintaining Connections</p>	<p><b>Connections to Home and Family.</b></p>

## References

- Adra, M., Hopton, J., and Keady, J. (2017). Nursing home quality of life in the Lebanon. *Quality in Ageing and Older Adults*. 18. <https://doi:10.1108/QAOA-01-2016-0002>.
- Age UK (2017) Later life in the United Kingdom. Accessed 11. 09.19. Available at: [https://www.ageuk.org.uk/Documents/EN-GB/Factsheets/Later\\_Life\\_UK\\_factsheet](https://www.ageuk.org.uk/Documents/EN-GB/Factsheets/Later_Life_UK_factsheet).
- Alzheimer's Research UK. (2019). About Dementia Statistics Hub. [Accessed 25.07.20]. Available at: <https://www.dementiastatistics.org/about/>
- Andersson, I., Pettersson, E., and Sidenwall B. (2007) Daily life after moving into a care home – experiences from older people, relatives, and contact persons. *Journal of Clinical Nursing*, 16: 1712– 8.
- Andoh-Arthur, J. (2019). *Gatekeepers in Qualitative Research*. In P. Atkinson, S. Delamont, A. Cernat, J.W. Sakshaug, and R.A. Williams (Eds.), SAGE Research Methods Foundations. <https://doi:10.4135/9781526421036854377>
- Backhouse, T., Kenkmann, A., Lane, K., Penhale, B., Poland, F., and Killett, A. (2016). Older care-home residents as collaborators or advisors in research: a systematic review. *Age and Ageing*, 45(3), 337–345. <http://doi.org/10.1093/ageing/afv201>
- Barnett, K., Mercer, S.W., Norbury, M., Watt, G., Wyke, S., and Guthrie, B. (2012) Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *The Lancet*, 380 (9836), 37-43.
- Bazeley, P. 2013. *Qualitative Data Analysis: Practical Strategies*. London: Sage.
- Beck, C.T. (1993) Qualitative research: the evaluation of its credibility, fittingness, and auditability. *Western Journal of Nursing Research* 15, 263–266.
- Benoliel, J.Q. (1996). Grounded theory and nursing knowledge. *Qualitative Health Research* 6, 406–428.
- Bigonnesse, C., Beaulieu, M., Garon, S. (2014). Meaning of Home in Later Life as a Concept to Understand Older Adults' Housing Needs: Results from the 7 Age-Friendly Cities Pilot Project in Québec. *Journal of Housing for the Elderly*. 28. 357-382. 10.1080/02763893.2014.930367.
- Birks, M. and Mills, J. (2015) *Grounded theory: a practical guide*. 2nd ed. London: SAGE.

Bland, M. (2005) The challenge of feeling 'at home' in residential aged care in New Zealand. *Nursing Praxis in New Zealand* 21, 4 –12.

Böckerman, P., Johansson, E., and Saarni, S.I. (2012) Institutionalisation and subjective wellbeing for old-age individuals: is life really miserable in care homes? *Ageing and Society*, 32(07), 1176-1192.

Bowers, H., Clark A., Crosby, G., Easterbrook, L., Macadam, A., MacDonald, R., Macfarlane, A., Maclean, M., Patel, M., Runnicles, D., Oshinaike, T., and Smith, C. (2009) Older People's Vision for Long-Term Care. York: Joseph Rowntree Foundation. Available at: <http://www.jrf.org.uk/sites/files/jrf/older-people-vision-for-care-full.pdf>

Bowers, B., Nolet, K., Jacobson, N., (2015) THRIVE Research Collaborative. Sustaining Culture Change: Experiences in the Green House Model. *Health services research*, 51 Suppl 1(Suppl 1), 398-417.

Bradshaw, S., Playford, E., and Riazi, A. (2012). Living well in care homes: a systematic review of qualitative studies. *Age and Ageing*, 41(4), pp.429-440.

Brandburg, G.L. (2007) Making transition to nursing home life: A framework to help older adult adapt to the long-term care environment. *Journal of Gerontological Nursing* 33, 50-56.

Brandburg, G., Symes, L., Mastel-Smith, B., Hersch, G., and Walsh, T. (2013) Resident strategies for making a life in a nursing home: a qualitative study. *Journal of Advanced Nursing*, 69(4), 862-874.

Bridges, W. (2004) *Transitions: Making Sense of Life's Changes*. Cambridge Da Capo Press: Massachusetts.

Brooke, P., and Bullock, R. (1999). Validation of a six-item cognitive impairment test with a view to primary care usage. *International Journal Geriatric Psychiatry*. 14: 936-940.

Brownie, S., Horstmanshof, L., and Garbutt, R. (2014) Factors that impact residents' transition and psychological adjustment to long-term aged care: A systematic literature review. *International Journal of Nursing Studies*, 51(12), pp.1654-1666.

Bringer, J.D., Johnston, L.H., and Brackenridge, C.H. (2004). Maximising transparency in a doctoral thesis: The complexities of writing about the use of QSR\*NVIVO within a grounded theory study. *Qualitative Research*, 4: 247–265.

Bryant, A., and Charmaz, K. (2007). *The Sage handbook of grounded theory*. Thousand Oaks, CA: SAGE Publications. <https://doi.org/10.4135/9781848607941> .

Bryant, A., and Charmaz, K. (2007). Grounded theory in historical perspective: An epistemological account. In A. Bryant, and K. Charmaz (Eds.), *The SAGE handbook of grounded theory* (pp. 31– 57). Thousand Oaks, CA: SAGE Publications.  
<https://doi.org/10.4135/9781848607941>

Bryman, A. (2012). *Social research methods*, 4th ed. Oxford, UK: Oxford University Press.

Bryman, A. (2016) *Social Research Methods*. 5<sup>th</sup> Edition. Oxford. Oxford University Press.

CASP. (2013). CASP qualitative checklist. Critical Appraisal Skills Programme.  
<https://docs.wixstatic.com/ugd/dded8725658615020e427da194a325e7773d42.pdf>

Chao, S.Y., Lan, Y.H., Tso, H.C., Chung, C.M., Neim, Y.M. and Clark, M.J. (2008) Predictors of psychosocial adaptation among elderly residents in long-term care settings. *Journal of Nursing Research*, 16(2), 149-158.

Chapman, A. (2019) Thinking ahead? Exploring adult social care provision with older people in Northern Ireland. *Health Social Care Community*, 27: 161– 169.  
<https://doi.org/10.1111/hsc.12635>

Charmaz, K. (2006) *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*. Thousand Oaks, CA: Sage Publications.

Charmaz, K. (2008) *Grounded theory as an emergent method*. In: Hesse-Biber, S., Leavy, P. (eds.) *Handbook of Emergent Methods*, pp. 155–170. Guilford Press, New York.

Chenitz, W. C. (1983). Entry into a nursing home as status passage: A theory to guide nursing practice. *Geriatric Nursing*, 4(2), 92-97.

Chin, L., and Quine, S. (2012) Common factors that enhance the quality of life for women living in their own homes or in aged care facilities. *Journal of Women and Ageing*, 24, 269–279.

Chiovitti, R.F., and Piran, N. (2003) Rigour and grounded theory research. *Journal of Advanced Nursing*, 44, 4, 427-435.

Clark C.M., Sheppard, L., and Fillenbaum, G.G. (1999). Variability in annual Mini-Mental State Examination score in patients with probable Alzheimer disease: a clinical perspective of data from the Consortium to Establish a Registry for Alzheimer's Disease. *Archives of Neurology* 56:857-862.

Cleland J. A. (2017). The qualitative orientation in medical education research. *Korean Journal of Medical Education*, 29(2), 61–71.  
<https://doi.org/10.3946/kjme.2017.53>

Cooney, A. (2012) 'Finding home': A grounded theory on how older people 'find home' in Long-term care settings. *International Journal of Older People Nursing*, 7(3), 188-199.

Cooper, C., Booth, A., Varley-Campbell, J., Britten, N., and Garside, R. (2018). Defining the process to literature searching in systematic reviews: a literature review of guidance and supporting studies. *BMC medical research methodology*, 18(1), 85. <https://doi.org/10.1186/s12874-018-0545-3>

Corbin, J. (2009). *Taking an analytic journey*. In Morse, J.M., Stern, P.N., Corbin, J., Bowers B., Charmaz K., and Clarke, A. (Eds.), *Developing grounded theory: The second generation* (pp. 35–54).

Corbin, J., and Strauss, A. (2008) *Basics of Qualitative Research*, 3rd edn. Sage, Thousand Oaks, California.

Corbin, J., and Strauss, A. (2015). *Basics of qualitative research*, 4th Edition, Thousand Oaks, CA: Sage.

Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches* (3rd ed.). Thousand Oaks, CA: Sage.

Creswell, J.W. (2013). *Qualitative Inquiry and Research Design: Choosing Among the Five Approaches*. Thousand Oaks, CA: SAGE Publications, Inc.

Creswell, J.W. (2014) *Research Design: Qualitative, Quantitative and Mixed Method Approaches*. Fourth Edition. SAGE Publications Limited, Thousand Oaks, California.

Cronin, P., Ryan, F., and Coughlan, M. (2008). Undertaking a literature review: A step-by-step approach. *British Journal of Nursing* (Mark Allen Publishing), 17. 38-43. <https://doi.org/10.12968/bjon.2008.17.1.28059> .

Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. London, Thousand Oaks, Calif: Sage Publications.

Custers, A.F., Westerhof, G.J., Kuin, Y., Gerritsen, D.L., and Riksen-Walraven, J.M. (2012) Relatedness, autonomy, and competence in the caring relationship: The perspective of nursing home individuals. *Journal of Aging Studies*, 26, 319–326. doi: <https://doi.org/10.1016/j.jaging.2012.02.005>

Davies, S.L., Goodman, C., and Manthorpe, J. (2014). Enabling research in care homes: an evaluation of a national network of research ready care homes. *BMC Medical Research Methodology* 14, 47. <https://doi.org/10.1186/1471-2288-14-47>

Davies, S., and Nolan, M. (2006) 'Making it better': Self-perceived roles of family caregivers of older people living in care homes: A qualitative study. *International Journal of Nursing Studies*, 43: 281-291.



de Guzman, A., Lacorte, J., Lacsamana, A., Lagac, M., Laguador, J., Lapid, J., and Lee, L. (2012). Who Says there is No Life After Abandonment? A Grounded Theory on the Coping of Abandoned Filipino Elderly in Nursing Homes. *Educational Gerontology*, 38. 890-901. <https://doi/10.1080/03601277.2012.661329>.

Denzin, N. K., and Lincoln, Y. S. (Eds.). (2005). *Handbook of qualitative research*. (3rd ed.). Thousand Oaks, CA: Sage.

Denzin, N. K., and Lincoln, Y. S. (Eds.). (2008). *The landscape of qualitative research* (3rd ed.). Sage Publications, Inc.

Department of Health Social Services (DHSSNI) (1990) *People First: Community Care in Northern Ireland in the 1990s*. DHSS: Belfast.

Department of Health Social Services and Public Safety (DHSSPS) (2011). *Improving Dementia Services in Northern Ireland: A Regional strategy*. Belfast.

Department of Health Social Services and Public Safety (DHSSPS) (2006) *Caring for Carers – Recognising, Valuing and Supporting the Caring Role*. Belfast.

Department of Health Social Services and Public Safety (DHSSPS) (2006) *Safeguarding Vulnerable Adults Regional Policy and Guidance*. DHSSPS.

Department of Health Social Services and Public Safety (DHSSPS) (2010) *Living well: Dying well- A palliative and end of life care strategy for adults in NI*. DHSSPS.

Department of Health, Social Services and Public Safety (DHSSPS) (2011). *Transforming Your Care*. DHSSPS.

Department of Health Social Services and Public Safety (DHSSPS) (2013). *Service Framework for Older People*. DHSS Belfast.

Department of Health Social Services and Public Safety (DHSSPS). (2015). ‘*The Right Time, the Right Place*’ (Donaldson Report). Belfast, UK: DHSSPS.

Department of Health Social Services and Public Safety (DHSSPS). (2016). *Systems not structures—Changing health and social care (Bengoa Report)*. Belfast, UK: DHSSPS.

Dey, I. (1999) *Grounding Grounded Theory Guidelines for Qualitative Inquiry*, San Diego: Academic Press.

DiazOrdaz, K., Slowther, A., and Potter, R. (2013). Consent processes in cluster-randomised trials in residential facilities for older adults: a systematic review of reporting practices and proposed guidelines *BMJ Open* ;3: e003057. <https://doi/10.1136/bmjopen-2013-003057>

Dossa, A., Bokhour, B., and Hoenig, H. (2012). Care transitions from the hospital to home for patients with mobility impairments: patient and family caregiver experiences. *Rehabilitation Nursing*, 37(6): 277–85.

Ebrahim, I.Z., Dahlin-Ivanoff, S., Eklund, K., Jakobsson, A., and Wilhelmson, K. (2015) Self-rated health and health-strengthening factors in community-living frail older people. *Journal of Advanced Nursing*, 71(4), 825– 836. <https://doi:10.1111/jan.12579>

Ericson-Lidman, E., Larsson, L.L., and Norberg, A. (2014) Caring for people with dementia disease (DD) and working in a private not-for-profit residential care facility for people with DD. *Scandinavian Journal of Caring Sciences*. 28: 337–346.

Eika, M., Espnes, G.A., and Hvalvik, S. (2014). Nursing staff's actions during older residents' transition into long-term care facility in a nursing home in rural Norway. *International Journal of Qualitative Studies on Health and Well-being*, 9, 24105. <https://doi:10.3402/qhw.v9.24105>

Ellins J. Glasby J. Tanner D. McIver S. Davidson D. Littlechild R. Snelling I. Miller R. Hall K. Spence K. and co-researchers (2012). *Understanding and Improving Transitions of Older People: A User and Carer Centred Approach*. Southampton, National Institute for Health Research.

Ellis, J.M. (2010). Psychological transition into a residential care facility: older people's experiences. *Journal of Advanced Nursing*, 66:1159–1168.

Engward, H., and Davis, G. (2015). Being reflexive in qualitative grounded theory: Discussion and application of a model of reflexivity. *Journal of Advanced Nursing*, 71(7), 1530– 1538. <https://doi.org/10.1111/jan.12653>

Evans, G. L. (2013). A novice researcher's first walk through the maze of grounded theory: Rationalization for classic grounded theory. *Grounded Theory Review*, 12(1), 37–55.

Falk, H., Wijk, H., Persson, L., and Falk, K. (2012) A sense of home in residential care. *Scandinavian Journal of Caring Sciences*, 27(4), 999-1009.

Fitzpatrick, J.M., and Tzouvara, V. (2018). Facilitators and inhibitors of transition for older people who have relocated to a long-term care facility: A systematic review. *Health and Social Care in the Community*, 27(3), e57–e81. <https://doi.org/10.1111/hsc.12647>

Flick, U. (2014). *An introduction to qualitative research* (5th ed.). London: Sage Publications Ltd.

Foreman, M.D., Fletcher, K, Mion, L.C., Simon, L., and Niche, F. (1996). Assessing cognitive function: the complexities of assessment of an individual's cognitive status

are important in making an accurate and comprehensive evaluation. *Geriatric Nursing* (London);17(5):228–232. [https://doi:10.1016/S0197-4572\(96\)80210-2](https://doi:10.1016/S0197-4572(96)80210-2)

Fraher, A. and Coffey, A. (2011). Older people's experiences of relocation to long-term care. *Nursing Older People*, 23(10), 23-27.

Fuji, K.T., Abbott, A.A., and Norris, J.F. (2012). Exploring care transitions from patient, caregiver, and health-care provider perspectives. *Clinical Nursing Research*, 22(3): 258–74.

Gale, C.R., Cooper, C., and Sayer, A.A. (2015). Prevalence of frailty and disability: findings from the English Longitudinal Study of Ageing. [Accessed on 23.07.20]. Available at: <https://www.ifs.org.uk/publications/7910>

Gilbert, S., Amella, E., Edlund, B., & Nemeth, L. (2015). Making the Move: A Mixed Research Integrative Review. *Healthcare* (Basel, Switzerland), 3(3), 757-74. <http://doi:10.3390/healthcare3030757>

Glaser, B. (1978) *Theoretical Sensitivity*. Mill Valley, CA: Sociology Press.

Glaser, B. (1992) *Basics of Grounded Theory Analysis: Emergence versus Forcing*. Mill Valley, CA: Sociology Press.

Glaser, B. (1998) *Doing Grounded Theory: Issues and Discussions*. Mill Valley, CA: Sociology Press.

Glaser, B.G., and Strauss, A.L. (1967). *The discovery of grounded theory, Strategies for qualitative research*. Chicago: Aldine.

Goodman C, Baron NL, Machen I, Stevenson E, Evans C, Davies SL, Iliffe S. (2010): Culture, consent, costs, and care homes: enabling older people with dementia to participate in research. *Aging Mental Health*. 15 (4): 475-48.

Gough, D., Thomas, J., and Oliver, S. (2012). Clarifying differences between review designs and methods. *Systematic Reviews*, 1, 28. <https://doi:10.1186/2046-4053-1-28>

Graneheim, U.H., Johansson, A., and Lindgren, B. (2014) Family caregivers' experiences of relinquishing the care of a person with dementia to a nursing home: Insights from a meta-ethnographic study. *Scandinavian Journal of Caring Sciences*, 28 (2), 215-224.

Gubrium, J.F. (1997). *Speaking of life*. Charlottesville: University Press of Virginia. (Original work published 1975).

Gray, D. (2018) *Doing Research in the Real World*. 4th Edition. London. Sage.

Guba, E.G. and Lincoln, Y.S. (1981) *Effective Evaluation*. San Francisco: Jossey-Bass.

Guba, E.G. and Lincoln, Y.S. (1989) *Fourth Generation Evaluation*. Newbury Park: Sage.

Handberg, C., Nielsen, C., and Lomborg, K. (2015) Revisiting symbolic interactionism as a theoretical framework beyond the grounded theory tradition. *Qualitative Health Research*, 25, 8, 1023-1032.

Hanratty, B., Holmes, L., Lowson, E., Grande, G., Addington-Hall, J., Payne, S. (2012). Older adults' experiences of transitions between care settings at the end of life in England: a qualitative interview study. *Journal of Pain and Symptom Management* 44(1): 74–83

Harding, J. (2013). *Qualitative data analysis: From start to finish*. Thousand Oaks, CA: Sage Publications.

Heliker, D., and Scholler-Jaquish, A. (2006) Transition of new residents: Basing practice on residents' perspective. *Journal of Gerontological Nursing*, 32, 34-42

Hedayati, M.A.M., and Khazaei, M. (2014) An Investigation of the Relationship between Depression, Meaning in life and Adult Hope Procedia. *Social and Behavioral Sciences*, 114(21), 598-601.

Holloway, I., and Galvin, K. (2017) *Qualitative Research in Nursing and Healthcare*. Fourth edition. Wiley-Blackwell, Chichester.

Holton, J. (2007). *The coding process and its challenges*. In A. Bryant & K. Charmaz (Eds.), *The SAGE handbook of grounded theory* (pp. 265–289). London: Sage.

Horner, B and Grenade, L. (2007) Promoting positive staff-family relationships in residential aged care: a service provider perspective [online]. *Geriaction*, Vol. 25, No. 2, Jun: 5-12.

Houser, J. (2013). *Nursing Research: Reading, Using, and Creating Evidence*. 2nd ed. Burlington, MA: Jones and Bartlett Learning.

Houser, J. (2018). *Nursing research reading, using, and creating evidence* (4th ed.). Burlington, MA: Jones and Bartlett.

Hutchinson, S., Hersch, G., Davidson, H.A., Chu, A.Y.M. and Mastel-Smith, B. (2011) Voices of Elders: Culture and Person Factors of Residents Admitted to Long-Term Care Facilities. *Journal of Transcultural Nursing*, 22, 397-404.

Institute of Nursing and Health Research (2019). *Additional Notes and Guidance for the PhD thesis with Papers format*. Ulster University. Northern Ireland.

International Council of Nurses. (2006) Code of Ethics for Nurses. [Accessed on 12.08.20]. Available at: <http://www.icn.ch/about-icn/code-of-ethics-for-nurses/>.

Ismail, N., Kinchin, G., and Edwards, J. (2018). Pilot study, does it really matter? Learning lessons from conducting a pilot study for a qualitative PhD thesis. *International Journal of Social Science Research*, 6(1) 1-17.

Iwasiw, C., Goldenberg, D., Macmaster, E., McCutcheon, S., and Bol, N. (1996) Residents' perspectives of their first 2 weeks in a long-term care facility, *Journal of Clinical Nursing*, 5, 381-388

Iwasiw, C., Goldenberg, D., Bol, N. (2003). Resident and family perspectives. *Journal of Gerontological Nursing*, 29(1): 45–54.

James, I., Blomberg, K., and Kihlgren, A. (2014). A meaningful daily life in nursing homes - a place of shelter and a space of freedom: a participatory appreciative action reflection study. *BMC Nursing*: 13:19.

Janghorban, R., Latifnejad Roudsari, R., and Taghipour, A. (2014). Pilot study in qualitative research: The roles and values. *Hayat*, 19(4), 1-5.

Johnson, R., Popejoy, L., and Radina, M. (2010) Older adult's participation in nursing home placement decisions. *Clinical Nursing Research*, 19(4), 358-375.

Johnson, R., and Bibbo, J. (2014) Relocation decisions and constructing the meaning of home: A phenomenological study of the transition into a nursing home. *Journal of Aging Studies*, 30(1), 56-63.

Kagan, S.H., and Melendez-Torres, G.J. (2015). Ageism in nursing. *Journal of Nursing Management*, 23(5), 644-650. <https://doi.org/10.1111/jonm.12191>

Kao H.F., Travis S.S., and Acton, G.J. (2004) Relocation to a long-term care facility: working with patients and families before, during, and after. *Journal of Psychosocial Nursing and Mental Health Services* 42(3), 10–16.

Kelly, A., and Kenny, C. (2018). Unpaid Care. [Accessed on 20.07.20.] Available at: <https://researchbriefings.parliament.uk/ResearchBriefing/Summary/POST-PN-0582>

Kenny, M., and Fourie, R. (2014). Tracing the history of grounded theory methodology: From formation to fragmentation. *The Qualitative Report*, 19(52), 1-9.

Khan, O. (2015) Dementia and ethnic diversity: numbers and trends. In: J Botsford J, Harrison Denning K, eds. *Dementia, culture, and ethnicity: issues for all*. London: Jessica Kingsley Publishers.

Kim, S.Y.H., Karlawish, J.H.T., and Caine, E.D. (2002) Current state of research on decision-making competence of cognitively impaired elderly persons. *American Journal of Geriatric Psychiatry* 10:151-165.

Kingston, A., Comas-Herrera, A., and Jagger, C. (2018). Forecasting the care needs of the older population in England over the next 20 years: estimates from the Population Ageing and Care Simulation (PACSim) modelling study. *The Lancet. Public Health*, 3(9), e447–e455. [https://doi.org/10.1016/S2468-2667\(18\)30118-X](https://doi.org/10.1016/S2468-2667(18)30118-X)

Koch, T. (1994). Establishing rigour in qualitative research: The decision trail. *Journal of Advanced Nursing*, 19, 976–986. <https://doi:10.1111/j.1365-2648.1994.tb01177.x>

Koppitz, A., Dreizler, J., Altherr, J., Bosshard, G., Naef, R., and Imhof, L. (2017) Relocation experiences with unplanned admission to a nursing home: a qualitative study. *International Psychogeriatrics*, 29(3), 517-527.

Križaj, T., Warren, A., and Slade, A. (2018) "Holding on to What I Do": Experiences of Older Slovenians Moving into a Care Home. *The Gerontologist*, Volume 58, Issue 3, June 2018, Pages 512–520, <https://doi.org/10.1093/geront/gnw150>

Kvale, S. (2006) Dominance Through Interviews and Dialogues, *Qualitative Inquiry*, 12(3):480-500.

Kvale, S., Brinkmann, S. Eds (2009). *Interviews: Learning the Craft of Qualitative Research Interviewing*. 2nd ed. London: Sage Publications.

Lee, D.T. (1999). Transition to residential care: Experiences of elderly Chinese people in Hong Kong. *Journal of Advanced Nursing*, 30, 1118– 1126. <https://doi.org/10.1046/j.1365-2648.1999.01196.x>

Lee, D.T.F. (2001) Perceptions of Hong Kong Chinese elders on adjustment to residential care. *Journal of Interprofessional Care* 15, 235–244.

Lee, D.T.F., Woo, J., and Mackenzie, A. (2002) A review of older people's experiences with residential care placement. *Journal of Advanced Nursing*, 37, 19-27.

Lee, V., Simpson, J., and Froggart, K. (2013). A narrative exploration of older peoples transitions into residential care. *Aging and Mental Health*, 17(1), 48-56

Lincoln, Y.S., and Guba, E.G. (1985). *Naturalistic Inquiry*. Newbury Park. Sage Publications.

Lincoln, Y.S. and Guba, E.G. (2000). *Paradigmatic controversies, contradictions, and emerging confluences*. In Denzin, N.K. and Lincoln, Y.S. (2000). *Handbook of qualitative research*, London: Sage, Chapter 6, 163 – 188.

Lindley, S., and Wallace, J. (2015). Placing in Age: Transitioning to a New Home in Later Life. *ACM Transactions on Computer-Human Interaction (TOCHI)*, 22(4), 20.

Liu, Y.E., Norman, I.J., and While, A.E. (2015). Nurses' attitudes towards older people and working with older patients: An explanatory model. *Journal of Nursing Management*, 23(8), 965-973. <https://doi:10.1111/jonm.12242>.

Locke, K. (2001). *Grounded theory in management research*. London, Sage Publications.

Lovatt, M. (2018) Becoming at home in residential care for older people: a material culture perspective. *Sociology of Health and Illness*, 40, 2, 366– 78.

Luff, R., Laybourne, A. H., Ferreira, Z. and Meyer, J. (2015). A guide to research with care homes. *Quality in Ageing and Older Adults*, 16(4), pp. 186-194. <https://doi:10.1108/QAOA-06-2015-0027>

Marengoni, A., Angleman, S., Melis, R., Mangialasche, F., Karp, A., Garmen, A., Meinow, B., and Fratiglioni, L. (2011) Aging with multimorbidity: a systematic review of the literature. *Ageing Research Reviews*, 10(4), 430-439.

Marshall, E., and McKenzie, L. (2008). Adjustment to residential care: The experience of newly admitted residents to hostel accommodation in Australia. *Australian Occupational Therapy Journal*, 55: 123–132. <https://doi:10.1111/j.1440-1630.2007.00687.x>

Mayan, M.J. (2009). *Essentials of qualitative inquiry*. New York, NY: Left Coast Press.

Maz, J. (2013) Employing grounded theory approach: Core characteristics. *British Journal of Cardiac Nursing*, 8, 453-458.

Mears, C. (2017) *Chapter 21: In-depth interviews* in: Coe, R., Waring M., Hedges, L. and Arthur, J. (eds), *Research Methods and Methodologies in Education*. 2nd Edition. London, Sage.

Meleis, A.I., Sawyer, L., Im, E., Hilfinger Messias, D., and Schumacher, K. (2000) 'Experiencing transitions: An emerging middle-range theory', *Advanced Nursing Science*, 23(1), pp. 12 – 28.

Meleis, A.I. (2010). *Transitions Theory—middle range and situation specific theories in nursing research and practice*. New York: Springer Publishing Company.



- Merriam, S.B., and Tisdell, E.J. (2015). *Qualitative research: A guide to design and implementation*. John Wiley and Sons.
- Miles, B., and Huberman, A.M. (2009). *Qualitative data analysis*. Thousand Oaks (CA): Sage Publications Ltd.
- Mills, J., Bonner, A., and Francis, K. (2006). The development of constructivist grounded theory. *International Journal of Qualitative Methods*, 5(1), 25–35.
- Milliken, P. (2010). *Grounded Theory*. In Neil J. Salkind (Ed.), *Encyclopedia of Research Design*. (pp. 549-554). Thousand Oaks, CA: SAGE Publications, Inc. <http://dx.doi.org/10.4135/9781412961288.n169>
- McGhee, G., Marland, G.R., Atkinson, J. (2007) Grounded theory research: literature reviewing and reflexivity. *Journal of Advanced Nursing*, 60, 3, 334-342.
- McKenna, D., and Staniforth, B. (2017). Older people moving to residential care in Aotearoa New Zealand: Considerations for social work at practice and policy levels. *Aotearoa New Zealand Social Work*, 29(1), 28–40.
- Moe, A., Hellzen, O., Enmarker, I. (2013) “The meaning of receiving help from home nursing care,” *Nursing Ethics*, vol.20, no. 7, pp. 737–747.
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G. (2009). For the PRISMA Group: Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *British Medical Journal*, 339: <https://doi.org/10.1136/bmj.b2535> .
- Molony, S.L. (2010) The meaning of home: A qualitative metasynthesis. *Research in Gerontological Nursing*, 3(4), 291-307.
- Moore, K.D., and Ryan, A.A. (2017) ‘*The Lived Experiences of Nursing Home Residents in the Context of the Nursing Home as their ‘Home’*. A Grounded Theory Study. Main Report. Ulster University and Nursing Homes Ireland. Ulster University Repository.
- Morse, J.M. (2007) *Sampling in grounded theory*. In: Bryant A, Charmaz K. (eds) *The Sage handbook of grounded theory*. Thousand Oaks, CA: SAGE, pp. 229–244.
- Morse, J.M. (2009) *Exploring transitions*. *Qualitative Health Research* 19, 431.
- Morse, J.M., Stern, P.N., Corbin, J., Bowers, B., Charmaz, K., and Clarke, A.E. (2009) *Developing grounded theory: The second generation*. Walnut Creek, CA: Left Coast Press.
- Morse, J.M. (2015). “Data were saturated...”. *Qualitative Health Research*, 25(5), 587–588.



Mortenson, B. W., Sixsmith, A., Beringer, R. (2016). No place like home? Surveillance and what home means in old age\*. *Canadian Journal on Aging*, 35(1), 103-114. <https://doi:10.1017/S0714980815000549>

My Home Life (2020) <https://myhomelife.org.uk/resources/>

Nathaniel, A.K. (2006). Thoughts on the literature review and GT. *Grounded Theory Review*, 5(2/3), 35–41.

National Institute for Health and Care Excellence (NICE). (2015) Transition between inpatient hospital settings and community or care home settings for adults with social care needs (NG27). [Accessed 20.06.20]. Available at: <https://www.nice.org.uk/guidance/ng27/chapter/Recommendations#discharge-from-hospital> .

National Health Service England (2016) Enhanced Health in Care Homes Framework. [Accessed on 28.05.20]. Available at: <https://www.england.nhs.uk/publication/enhanced-health-in-care-homes-framework/>

Nicholson, C., Meyer, J., Flatley, M., Holman, C. and Lowton, K. (2012) Living on the margin: understanding the experience of living and dying with frailty in old age. *Social Science and Medicine* 75(8), 1426–1432. <https://doi:10.1016/j.socscimed.2012.06.011>

Nolan, M.R., Walker, G., Nolan, J., Williams, S., Poland, F., Curran, M., and Kent, B.C. (1996). Entry to care: positive choice or fait accompli? Developing a more proactive nursing response to the needs of older people and their carers. *Journal of Advanced Nursing*, 24, 2, 265–74.

Nolan, M.R., Hanson, E., Magnusson, L., and Anderson, B. (2003) Gauging quality in constructivist research: the Aldre Vast Sjuharadmodel revisited. *Quality in Ageing*, 4, 22–27.

Nolan, M., Brown, J., Davies, S., Nolan, J., and Keady, J. (2006). *The SENSES framework: Improving care for older people through a relationship-centred approach*. University of Sheffield. ISBN 1-902411-44-7.

Northern Ireland Audit Office (2017). *Management of the Transforming Your Care Reform Programme*. Report by the Comptroller and Auditor General, 11.04.17. [Accessed on 25.11.19]. Available at: <https://www.niauditoffice.gov.uk/sites/niao/files/media-files/Management%20of%20the%20Transforming%20Your%20Care%20Reform%20Programme.pdf>

Northern Ireland Human Rights Commission. (2012) *In Defence of Dignity -The Human Rights of Older People in Nursing Homes* (NIHRC).

Northern Ireland Statistics and Research Agency (NISRA). (2018). Estimates of the population aged 85 and over in Northern Ireland, by age and sex. [Accessed on 23.07.20]. Available at: <https://www.nisra.gov.uk/statistics/population/estimates-population-aged-85-and-over>

NVivo qualitative data analysis Software, QSR International Pty Ltd. Version 12, 2018.

Nwe, W.T., D'Souza, G., and Sheehan, B. (2011) Expectations and experience of moving to a care home: Perceptions of older people with dementia. *Dementia* (14713012), 10 (1), 7-18.

Office for National Statistics (ONS) (2018k). *Living longer-*. [Accessed on 23. 07.20]. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriage/s/ageing/articles/livinglongerhowourpopulationischangingandwhyitmatters/2018-08-13>

O'Neill, M., Ryan, A., Slater, P.F., Ferry, F.R., and Bunting, B. (2020) Mental Health, Quality of Life and Medication Use Among Care Home Residents and Community Dwelling Older People. *International Journal of Research in Nursing*, 10, p.10-23 14 p. <https://doi.org/10.3844/ijrnsp.2019.10.23>

O'Neill, M., Ryan, A., Tracey, A., and Laird, L.E.A. (2020) “You’re at their mercy”: Older peoples’ experiences of moving from home to a care home: A grounded theory study. *International Journal of Older People Nursing*, [e12305]. <https://doi.org/10.1111/opn.12305>.

O'Neill, M., Ryan, A., Tracey, A., & Laird, L. (2020). ‘Waiting and Wanting’: Older peoples’ initial experiences of adapting to life in a care home: A grounded theory study. *Ageing and Society*, 1-25. <https://doi:10.1017/S0144686X20000872>.

O'Neill, M., Ryan, A., Tracey, A., & Laird, L. (2020). ‘The Primacy of ‘Home’: An exploration of how older adults’ transition to life in a care home towards the end of the first year. *Health and Social Care in the Community*. [In Press].

Österlind J, Ternstedt B-M, Hansebo G, Hellström I. (2017) Feeling lonely in an unfamiliar place: older people’s experiences of life close to death in nursing home. *Int J Older People Nursing*. <https://doi.org/10.1111/opn.12129>.

Paddock, K., Brown Wilson, C., Walshe, C.E. and Todd, C. (2018) Care home life and identity: A qualitative case study. *The Gerontologist* 59, 655-664. <http://doi.org/10.1093/geront/gny090>

Parahoo, K. (2014) *Nursing research: principles, process, and issues*. 3rd ed. Hampshire: Palgrave Macmillan.

Polit, D.F., and Beck, C.T. (2012). *Nursing research: generating and assessing evidence for nursing practice*. 9th ed. Philadelphia, PA: Lippincott Williams and Wilkins.

Polit, D. F., and Beck, C.T. (2014). *Essentials of nursing research: appraising evidence for nursing practice*. New York, U. S. A.: Lippincott, Williams & Wilkins.

Polit, D.F., and Beck, C.T. (2017). *Nursing research: Generating and assessing evidence for nursing practice* (10th ed.). Philadelphia, PA: Williams and Wilkins.

Porter, E.J. and Ganong, L. (2005) Older widows' speculations and expectancies concerning professional home-care providers. *Nursing Ethics*, 12, 507-21.

Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, A., Salimkumar, D. (2014). *Dementia UK: Update*. (2nd edn), Alzheimer's Society.

Ralph, N., Birks, M., and Chapman, Y. (2015). The methodological dynamism of grounded theory. *International Journal of Qualitative Methods*, 14(4), 1– 6. <https://doi.org/10.1177/1609406915611576>

Reed, J., and Payton, V.R. (1997). Understanding the dynamics of life in care homes for older people: Implications for de-institutionalizing practice. *Health and Social Care in the Community*, 5, 261– 268. <https://doi.org/10.1111/j.1365-2524.1997.tb00122.x>

Reed, J., Cook, G. and BurrIDGE, C., (2002). 'Loss and change.' In: Hockley, J. and Clark, D., 2002. *Facing Death: Palliative Care for Older People in Care Homes*. Buckingham: Open University Press.

Regulation and Quality Improvement Authority (RQIA) (2018) *Registered Nursing and Residential Homes and Beds Trend Report 2008 – 2018*. [Accessed on 23.11.19]. Available at: <https://www.rqia.org.uk/RQIA/files/0f/0ff745be-514f-4013-8309-7d63de74bbc1.pdf>

Regulation and Quality Improvement Authority, (RQIA) (2020). [Accessed on 25.04.20]. Available at: <https://www.rqia.org.uk/guidance/guidance-for-the-public/frequently-asked-questions-for-public/>

Rijnaard, M.D., van Hoof, J., Janssen, B.M., Verbeek, H., Pocornie, W., Eijkelenboom, A., Beerens, H. C., Molony, S.L., and Wouters, E.J. (2016). The Factors Influencing the Sense of Home in Nursing Homes: A Systematic Review from the Perspective of Residents. *Journal of Aging Research*, 2016, 6143645. <https://doi.org/10.1155/2016/6143645>

Rioux, L., and Werner, C. (2011) Residential satisfaction among aging people living in place. *Journal of Environmental Psychology*, 31(2), 158-169.

Roberts, T. and, Bowers, B. (2015) How nursing home residents develop relationships with peers and staff: A grounded theory study. *International Journal of Nursing Studies*, 52: 57–67.

Royal Society of Public Health (2018) That Age Old Question, London. [Accessed on 25.07.20]. Available at: <https://www.rsph.org.uk/our-work/policy/older-people/that-age-old-question.html>

Ryan, A., and McKenna, H. (2015) “it’s the little things that count’. Families experience of roles, relationships, and quality of care in nursing homes. *International Journal of Older People Nursing*, 10, 38-47. <http://DOI:1111/opn.12052> .

Saks, M., Allsop, J. (2013). *Researching Health: Qualitative, Quantitative and Mixed Methods*. 2nd Edition. London: Sage.

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science*, 8, 27–37.

Saunders, J.C. and Heliker, D. (2008) Lessons learned from 5 women as they transition into assisted living. *Geriatric Nursing*, 29, 369–375.

Sebastian, K. (2019). Distinguishing Between the Strains Grounded Theory. *Journal for Social Thought*, 3(1).

Schreiber, R.S. (2001) *The ‘how to’ of grounded theory: avoiding the pitfalls*. In Using Grounded Theory in Nursing (Schreiber R.S. and Stern P.N. eds). Springer, New York, pp. 55–84.

Schumacher, K., and Meleis, A. (2010) ‘*Transitions: A central concept in nursing*’, in A. Meleis (ed.), *Transitions Theory: Middle Range and Situation-Specific Theories in Nursing Research and Practice*, New York, Springer Publishing, pp. 38 – 51.

Shear, M. K., Ghesquiere, A., and Glickman, K. (2013). Bereavement and complicated grief. *Current Psychiatry Reports*, 15(11), 406. <https://doi.org/10.1007/s11920-013-0406-z>

Shin J.H. and Hyun, T.K. (2015) Nurse staffing and quality of care of nursing home residents in Korea. *Journal of Nursing Scholarship*, 47 (6), 555– 564.

Silverman, D. (2013) What Counts as Qualitative Research? Some Cautionary Comments. *Qualitative Sociology Review*, 9(2):48-55.

Social Care Institute For Excellence (2020) Freedom to Choose and Dignity in Care. [Accessed on 13.08.20]. Available at: <https://www.scie.org.uk/dignity/care>

Spencer, J., and Hersch, G. (2000). *Cultural heritage interview guide*. Unpublished instrument.

Stevens, A., Raphael, H., and Green, S.M. (2015). A qualitative study of older people with minimal care needs experiences of their admission to a nursing home with Registered Nurse care. *Quality in Ageing in Older Adults*, 16 (2), 94-105.

Strauss, A. (1987) *Qualitative Analysis for Social Scientists*. Cambridge, UK: University of Cambridge Press.

Strauss, A., and Corbin, J. (1990) *Basics of Qualitative Research* (1st Edn.). Thousand Oaks: CA: Sage.

Strauss, A., and Corbin, J. (1994) *Grounded theory methodology*. In Denzin. N. K. and Lincoln, Y. S. (Eds.) *Handbook of Qualitative Research*. Thousand Oaks: Sage.

Strauss, A., and Corbin, J. (1998) *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* (2nd Ed.). Thousand Oaks: London.

Sullivan, G.J., and Williams, C. (2017) Older adult transitions into long-term care. *Journal of Gerontological Care*, 43, 41– 49. <https://doi.org/10.3928/00989134-20161109-07>

Sury, L., Burns, K., and Brodaty, H. (2013) Moving in: adjustment of people living with dementia going into a nursing home and their families. *International Psychogeriatrics*, 25(6), 867-876

Sussman, T., and Dupuis, S. (2014) Supporting Residents Moving Into Long-Term Care: Multiple Layers Shape Residents' Experiences. *Journal of Gerontological Social Work*, 57 (5), 438-459.

Swift, H.J., Abrams, D., Lamont, R.A., Drury, L. (2017) The Risks of Ageism Model: how ageism and negative attitudes toward age can be a barrier to active aging. *Social Issues and Policy Review*, 11: 195–231.

Tanner, D., Glasby, J., McIver, S. (2015). Understanding and improving older people's experiences of service transitions: Implications for social work. *British Journal of Social Work*, 45(7), 2056–2071. <https://doi:10.1093/bjsw/bcu095>

Tappen, R.M. (2011). *Advanced Nursing Research: from Theory to Practice*. Sudbury: Jones and Bartlett Learning.

Tavares-Júnior, J., de Souza, A., Alves, G. S., Bonfadini, J. C., Siqueira-Neto, J. I., & Braga-Neto, P. (2019). Cognitive Assessment Tools for Screening Older Adults With Low Levels of Education: A Critical Review. *Frontiers in psychiatry*, 10, 878. <https://doi.org/10.3389/fpsy.00878>

Tester, S., Hubbard, G., Downs, M., MacDonald, C., and Murphy, J. (2004). What does quality of life mean for frail residents? *Nursing and Residential Care*, 6, 89–92. <https://doi:10.12968/nrec.2004.6.2.12052>

Thein, N.W., D'Souza, G., and Sheehan, B. (2011). Expectations and experience of moving to a care home: perceptions of older people with dementia. *Dementia*, 10, 7–18.

Tiwari, S.C., Tripathi, R.K., and Kumar, A. (2009) Applicability of the mini-mental state examination (MMSE) and the Hindi mental state examination (HMSE) to the urban elderly in India: a pilot study. *International Psychogeriatr*;21(1):123–128. <https://doi:10.1017/s1041610208007916> PMID: 18983719

Toles, M.P., Abbott, K.M., Hirschman, K.P. and Naylor, M.D. (2012). Transitions in care among older adults receiving long-term services and supports. *Journal of Gerontological Nursing*, 38(11): 40–7.

United Nations, Department of Economic and Social Affairs, Population Division (2019a). *World Population Ageing 2019: Highlights* (ST/ESA/SER.A/430)

United Nations, Department of Economic and Social Affairs, Population Division (2019b). *World Population Prospects 2019: Highlights*. ST/ESA/SER.A/423

Urquhart, C., Lehmann, H., Meyers, M. (2010) Putting the 'theory' back into grounded theory: guidelines for grounded theory studies in information systems. *Information Systems Journal*, 20(4), 357–381.

Urquhart, C. (2013) *Grounded Theory for Qualitative Research: A Practical Guide*. Sage, Thousand Oaks.

Van Humbeeck, L., Dillen, L., Piers, R., and Van Den Noortgate, N. (2016). Grief and loss in older people residing in nursing homes: (un)detected by nurses and care assistants? *Journal of Advanced Nursing*, 72(12), 3125–3136.

van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. Albany: State University of New York Press.

Van Ness, P.H., Peduzzi, P.N., Quagliarello, V.J. (2012) Efficacy and effectiveness as aspects of cluster randomized trials with nursing home residents: methodological insights from a pneumonia prevention trial. *Contemporary Clinical Trials*,33(6):1124–1131. <https://doi:10.1016/j.cct.2012.08.004>.

Voutilainen, P., Backman, K., Isola, A., and Laukkala, H. (2006). Family Members' Perceptions of the Quality of Long-Term Care. *Clinical Nursing Research*, 15(2), 135–149. <https://doi.org/10.1177/1054773805285697>



Walker, E., and McNamara, B. (2013). Relocating to Retirement Living: An Occupational Perspective on Successful Transitions. *Australian Occupational Therapy Journal*, 60, 445-453.

Walls, P., Parahoo, K., Fleming, P. (2010) The role and place of knowledge and literature in grounded theory. *Nurse Researcher*, 17, 4, 8-17.

White, N., Scott, A., Woods, R.T., Wenger, G.C., Keady, J. and Devakumar, M. (2002). The limited utility of the Mini-Mental State Examination in screening people over the age of 75 years for dementia in primary care. *British Journal of General Practice*, 52(485): 1002-1003.

Whittemore, R., and Knafl, K. (2005) "The integrative review: updated methodology," *Journal of Advanced Nursing*, vol. 52, no. 5, pp. 546–553.

Wiersma, E., and Dupuis, S.L. (2010). Becoming institutional bodies: Socialization into a long-term care home. *Journal of Aging Studies*, 24, 278–291. <https://doi.org/10.1016/j.jaging.2010.08.003>

Wilson, S.A. (1997) The transition to nursing home life: a comparison of planned and unplanned admissions, *Journal of Advanced Nursing*, 26, 864-871

Wilson, C.B., and Clissett, P. (2011). Involving older people in research: practical considerations when using the authenticity criteria in constructivist inquiry. *Journal of Advanced Nursing*, 67(3), 677–686. <https://doi:10.1111/j.1365-2648.2010.05500.x>

Wilson E, Pollock K, Aubeeluck A. (2010): Gaining and maintain consent when capacity can be an issue: a research study with people with Huntington's Disease. *Clinical Ethics*. 5 (13): 142-147.

Wirral, F. (2018). *Frailty*. [Accessed on 23.07.20]. Available at: [https://www.wirralintelligenceservice.org/media/2510/frailty\\_review\\_final\\_7-8-2018.pdf](https://www.wirralintelligenceservice.org/media/2510/frailty_review_final_7-8-2018.pdf)

Wittenberg, R., Hu, B., Barraza-Araiza, L. (2019) *Projections of Older People Living with Dementia and Costs of Dementia Care in the United Kingdom 2019-2040*. CPEC Working Paper 5. London School of Economic and Political Science, London.

Wood, R., Giuliano, K., Bignell, C., and Pritham, W. (2006). Assessing Cognitive Ability in Research: Use of MMSE with Minority Populations and Elderly Adults with Low Education Levels. *Journal of gerontological nursing*. 32. 45-54. <https://doi:10.3928/00989134-20060401-08>.

Wood, F., Prout, H., Bayer, A., Duncan, D., Nuttall, J., Hood, K. (2013) Consent, including advanced consent, of older adults to research in care homes: a qualitative study of stakeholders' views in South Wales. *Trials*, 14(1):247. <https://doi:10.1186/1745-6215-14-247>.

World Health Organisation. (2015). World report on ageing and health. Retrieved from [http://apps.who.int/iris/bitstream/handle/10665/186463/9789240694811\\_eng.pdf?sequence=1](http://apps.who.int/iris/bitstream/handle/10665/186463/9789240694811_eng.pdf?sequence=1)

World Health Organization (2018). *Global consultation on integrated care for older people (ICOPE)—the path to universal health coverage: report of consultation meeting 23–25 October 2017 in Berlin, Germany*. Geneva. [Accessed on 21.11.19]. Available at: <file:///C:/Users/e10247218/AppData/Local/Microsoft/Windows/INetCache/IE/LZ7H9HER/WHO-FWC-ALC-18.3-eng.pdf>

World Health Organization (2020) Dementia: Key Facts. <http://www.who.int/news-room/fact-sheets/detail/dementia> (Last accessed: 25 October 2020.)

Zamanzadeh, V., Rahmani, A., Pakpour, V., Chenoweth, L.L. and Mohammadi, E. (2016) Psychosocial changes following transition to an aged care home: qualitative findings from Iran. *International Journal of Older People Nursing*, 1-10.